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# Operationalizing Family Centered Practice: Utilization of Data from an Intervention Study

by

Kimberley Gayle Cook

A thesis submitted to the Faculty of Graduate Studies and Research in partial completion of the requirements for the degree of Master of Nursing

Faculty of Nursing

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## SETTING THE EXAMPLE

I'd rather see a sermon than hear one--any day.
I'd rather you would walk with me, than merely show the way.
The eye's a better pupil and more willing than the ear,
Fine counsel is confusing, but example is always clear.
The best of all the teachers are parents who live their creeds.
For, to see good in action is what every child needs.
I can say, I'll learn how to do it if you'll let me see it done;
I can watch your hand in action though your
tongue too fast may run.
Although the lectures you deliver may be very wise and true,
I'd rather learn my lesson by observing what you do;
For I may misunderstand you and the fine
advice you give,
But there's no misunderstanding how
you act and how you live.

-Author Unknown-

Each child is a new being,
a potential prophet,
a new spiritual prince,
a new spark of life
precipitated into the outer darkness.
Who are we to decide that it is hopeless?

-R.D. Laing-

## Dedication

To Stewart,
Who supported me in all stages of this thesis,
who had faith when I faltered,
knowing I could do it even when I didn't,
praise and inspiration when I doubted,
and love and friendship always.

To Emily and Benjamin,
For the joy you bring me on a daily basis.
"Mommy's done on the 'puter for awhile..."

To my parents and the rest of my family,
Thank you for things too numerous to mention,
including an ongoing belief in my abilities.

To the families,
Thank you for allowing me into your homes.

Abstract

Family centered practice (FCP) is one approach health professionals can take in working with families. There are accepted benefits of, criteria for, and measurements of FCP; however, missing are specific FCP interventions and information on their implementation. The purpose of this qualitative study is to look at the 'family centeredness' of two interventions (Natural Teaching Strategies and Co-operative Family Learning); to describe and compare the experiences of participants; and to determine how these experiences inform our understanding of FCP. In addition to data from the original study, the researcher interviewed a convenience sample of families, as well as administered questionnaires via email (one researcher was interviewed) to the researchers and interventionists. Comparative, content, and question analysis were used to answer the research questions. Two major findings of this study have become issues of interest: 1) the notion that the skill building aspects of the interventions are separate from, but related to, FCP; and, 2) that a second theme that recurred throughout the data is that of fluency. These findings are discussed in the context of the literature, as well as in terms of implications for nursing practice, education, research, the interventions and FCP. Strengths and limitations of the research process are acknowledged.

**Acknowledgements**

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# Chapter 1

## Introduction

It is commony believed that early life experiences are critical in the development of all children. Acknowledgement of this fact makes it necessary to incorporate families, as the context within which the child grows and develops, into the care of children with special needs, as early as possible. Family centered practice (FCP) can be viewed as early intervention or prevention of future difficulties, particularly with at risk families of children with mild to moderate developmental delay. The 'risks' in this study are, as they were in the original study: parental education less than grade ten; family income less than $20,000 a year; divorced or lone parent status; and substance or other abuse practices. These families face the normative stressors common to many families with children, as well as unique demands related to their risks.

Incorporating families into prevention and treatment has been documented in the health and social sciences literature as being beneficial to families and their children long before FCP was an established approach with a name of its own. In particular, pediatric health care in the mid-1960's underwent changes due in part to the deinstitutionalization movement, as well as the recognition that the developmental and emotional needs of children were better served when parents were included in the care of their children (Broadwell Jackson & Saunders, 1993). Currently, there is acknowlegement, and increased understanding of, the important role families play in the health care of children. Incorporating families into the care of childen has become the norm, and is considered an essential component of health care for children and their families.

There are nine commonly accepted principles of FCP outlined in the literature (Shelton & Stepanek, 1994) (Appendix A), which were further reduced to five for evaluative purposes in this study (see discussion under Components and Criteria of FCP). Despite this recognition, ambiguity still surrounds the term, and thus there is inadequate

research on what constitutes FCP. Uneven application of the principles leaves researchers and practitioners without acceptable measurements, a common language or practice base.

## Purpose

The purpose of this study is threefold: first, to look at the 'family centeredness' (i.e., using the five FCP principles as a gauge) of the interventions used in the original study; second, to describe and compare the experiences of those who took part in the original study; and third, to determine how the experiences of those who took part in the original study informs our understanding of FCP. Three research questions postulated below expand on the purpose of the study:

1. How was FCP implemented in the original study?
2. How was FCP experienced by the families in the original study?
3. How do the facts of implementation of FCP in the original study; and the researchers', interventionists', and families' reported experience of FCP, inform understanding of FCP?

## Definition of Terms

Family (from original study)

Whatever the primary caregiver considered their family composition to be. Parents, guardians, grandparents, and siblings, and any family relative or friend who is significantly involved with the child's everyday life (Bruce, 1993).

At risk (from original study)

Used to describe families who had two or more of the following characteristics: parental education less than grade ten; family income less than $20,000.00 per year; divorced or lone parental status; and substance, or other, abuse practices.

Developmental delay (from original study)

Six month or more delay in two or more areas of development (communication, social and behavioural) as assessed by the Diagnostic Instrument for Screening Children (DISC) (Amdur, Mainland & Parker, 1988).

Special needs

Additional optimal requirements of families of children with a developmental delay, due to the delay and 'at risk' factors beyond those usually expected for children of a particular age.

## Conceptual Framework

This study was developed within the framework of family centered care as proposed by the ACCH (Shelton & Stepanek, 1994), and by the Family-Centered Care Committee at the Izaak Walton Killam Hospital for Children (1992).

# Chapter 2

## Literature Review

The concepts of family centered practice (FCP), family resiliency and adaptation, as well as measurements of FCP, and the interventions used in the original study were explored through an extensive review of nursing as well as the health and social sciences literature. Computer data bases searched include: CINAHL, Medline, Canadian Education Index, ERIC, PsycInfo and Sociofile. Most of the articles reviewed are research in nature with publication dates ranging from 1945 to 1998. Relevant books were also included in this review.

Family centered practice and other related terms such as family participation and parental involvement have been in nursing and other health and social sciences literature for over three decades. Although these terms are used in everyday practice, their meanings vary. Family centered practice has become a specific approach used in nursing and other disciplines in interacting with families in a variety of settings. Although there are lists of characteristics that constitute FCP, how is it operationalized in practice? In this study, one system of approaches to FCP will be examined. The review of the literature covered the following areas: children with developmental delay (identified as a disability), families at risk, the concept of FCP, tools to assess for FCP, and the two strategies used in the original study (Co-operative Family Learning and Natural Teaching Strategies). A subsequent section addresses the theoretical underpinnings and specific model used in the original study.

## Family Centered Practice

### Practical Sources of FCP

#### Typical Client Foci of Family Centred Practice

The literature on FCP typically revolves around families of children with special needs, often due to low birth weight or disability, that have the potential to delay some aspect of development; and families at risk for health and social problems. These are the

families and children that are part of the future of our nation, and they are also the families that put a great amount of strain on our health and social systems. The total cost estimate to Canadians is unknown, but is considered to be enormous. Children have been recognized in many initiatives as Canada's greatest resource, and most recently in the *Final Report of the National Forum on Health* (Health Canada, 1997), which regards it to be urgent to "help children develop resiliency and foster development of parental competence" in order to lessen these health and social problems, and their costs. These documents unanimously recommend investing in families and their children by supporting them, and in turn improving our overall health. Our future is in jeopardy if a solution for these families is not found.

Families of Children with Special Needs. Current statistics on the occurrence of low-birth weight infants and childhood disability give a disturbing picture of the immensity of this problem. In Canada, 5.5% of newborn infants, or approximately 22,000 annually, are of low birth weight (<2500 g). Included in this number are two subgroups of infants who face a greater risk: those classified as very low birthweight (<1500 g), almost 1% of all infants (3,800 annually), as well as those who are full-term but small for gestational age, almost 2% of all infants (7,700 annually) [Canadian Institute of Child Health (CICH), 1994].

Low birthweight puts children at significant risk for death, chronic health problems, and disability. In addition, the results of the Ontario Child Health Study show that children with selected psychiatric disorders are 2.5 times more likely to have been of low birth weight compared to children without these psychiatric disorders (Offord, 1989). The fact that low birth weight is directly related to future health and social problems has been well established in the literature.

Besides low birthweight, childhood disability is a reason for families to be classified as having special needs. Disability can be present at birth or may be acquired through accidents and chronic illness. Nationally, 7.2% of children aged 0-19 years are

disabled (CICH, 1994). The prevalence varies from region to region. In Alberta the rate is 9.3% (CICH, 1994).

Like families of low birth weight infants, members of families with children having disabilities face particular risks to their physical and emotional health. Mothers are characterized as having higher levels of depression and lower levels of perceived maternal competence (Breslau & Davis, 1986; Goldberg, Marcovitch, MacGregor, & Lojkasek, 1986). Avoidance, wishful thinking, and adjustment difficulties have also been found among mothers (Frey, Grenberg & Fewell, 1989). Fathers also have their issues, as they have been reported to have feelings of inadequacy (McConkey, 1985), which places the mother under additional stress as she tries to meet the needs of the father and the children. Higher levels of anxiety and need for coping have been found in both parents (Hodges & Parker, 1987), and siblings (Kruger; 1980; Pinyers, 1983; Taylor, 1980). Although the majority of researchers focus on negative effects on the family due to chronic conditions or disabilities, it should be noted that the effect on the marital relationship was postive in five of ten fathers in a study by McKeever (1981). Taylor (1980) found that one third of the siblings derived some benefit from having a brother or sister with a chronic illness or disability. In general, these studies reflect the impact individual family members have on the entire family unit.

Families at Risk. Families at risk are those who are experiencing one or more of the following factors: poverty, single parent families, low parental education, and substance/physical abuse. Income has been well established as a key underlying determinant of health and well being. "People who live in bad housing, who eat bad food and cannot afford decent clothing, get sick" (Adams, Cameron, Hill, & Penz, 1971). Infant death rates are higher in poor neighbourhoods than in high income neighbourhoods (Adams, Cameron, Hill, & Penz, 1971; Edmonton Board of Health (EBH), 1989). Children living in poverty are more likely to die from accidental injuries; have chronic health problems; be admitted to hospital; suffer from poor nutriton; have school or

psychiatric problems; and have lower self-esteem than children who do not live in poverty (Adams, Cameron, Hill, & Penz, 1971, CICH, 1994; EBH, 1989; Harding, 1987; Plichta & Weisman, 1995; Strickland & Giger; 1994). Also, most households headed by single mothers are affected by poverty (CICH, 1994). In 1990, Alberta had approximately 62% of children in female led families living in poverty (Edmonton Social Planning Council, 1993, 1994), a number constantly on the rise.

Low income and child poverty are linked to the head of the household having limited education. Fifty-nine percent of Canada's poor children under eight years of age live in homes where the head of the household has attained a high school diploma or less (Adams, Cameron, Hill, & Penz, 1971; CICH, 1994). In Edmonton, over half of single mothers have less than a grade nine education (CICH, 1994).

The aforementioned risk factors have also been associated with substance and, or, physical abuse. Although the rates of these types of abuse often appear higher in at-risk families, it may be due to the fact that these families typically have increased contact with a system that identifies such abuse, or the fact that they are often "subjected to higher rates of surveillance than higher income families" (Blackburn, 1991). The detrimental effects of both physical and substance abuse on individuals, children, and families have been well examined in the literature and will not be discussed further here.

It is important to note that risk factors typically co-occur, and their effects together are particularly hazardous as they may be synergistic (i.e., implies a much more complex relationship between factors that cannot be reduced to a formula) rather than simply additive or multiplicative. Although there support for risk factors co-occuring in the literature, three landmark sets of studies, conducted in different regions, with various populations, highlight the phenomenon of multiple risk factors associated with the environment in which children grow up (Offord, 1989; Rutter, 1979; Werner & Smith, 1982). The authors conclude in all three studies that environment is a powerful determinant of the health of children. In addition, pioneering research suggests that early intervention is optimal during

a 'critical period', or window of opportunity, prenatally to approximately age six when the developing brain is so malleable "...it can incorporate behavioural problems into its circuits as readily as it might pick up a love of music" (Begley, S., 1996; Hotz, R., year unknown). Studies have shown that although it is never too late to stimulate a child's development, the old adage 'the earlier the better' holds very true.

Thus, as families with special needs are under tremendous stress, both intense and chronic, their adaptive abilities are taxed. Therefore, to improve the health of these children and their families, it is logical to concentrate on health promotion programs involving the family and the family's adaptive abilities. Ideally, these programs should enhance the family's ability to adapt successfully when facing the challenges of life and of child-rearing.

Issues of Risk and Adaptation. One of the areas nursing and other disciplines have struggled with is uncovering why some families are better than others at dealing positively with adversity; negotiating their way through transitions and tragedies; and coping with, and even thriving on, life's hardships (Friedman, 1992; McCubbin & McCubbin, 1991; McCubbin & McCubbin, 1993; McCubbin & Patterson, 1981). Adaptation can be described as a continuum of responses to a given stressor. Research has focused on resiliency as being a major force in the response families have to stressors. Resiliency has been defined as the capability of individuals, families, groups, and communities to adapt *positively* in the face of risk (Mangham, Reid, McGrath, & Stewart, 1994), and is being attributed to the ability to overcome extreme stress and adversity, and maintaining the integrity of the family unit (McCubbin, Thompson, & McCubbin, 1996). The major finding in adaptation and resiliency research is that the majority of families, even those facing high stressors, do adapt (McCubbin, Thompson & McCubbin, 1996), and adapt positively. Those families experiencing high stress due to normative stressors, children with special needs, and certain risk factors, tend to exhibit certain characteristics.

There are six essential patterns of behaviour, or family functioning in families that offer protection for child health. That is, resilient families have the following strengths: flexibility; stability in structure; family problem solving; effective parenting; social support networks; and links with the community (Drummond, Kysela, Alexander, McDonald, & Query, 1996). These six protective patterns of family behaviour, along with indicators of child health and development, are the outcomes of programs that focus on family strengths rather than weaknesses. Successful adaptation occurs when people achieve a balance between risk factors and protective mechanisms (McCubbin, Thompson, & McCubbin, 1996). Major barriers to successful adaptation can basically be construed as the opposite of the six protective patterns of family behaviour (Gray & Holden, 1992; Rodrigue, Morgan, & Geffken, 1992; Snowdon, Cameron, & Dunham, 1994). Thus, health programs take one of two approaches: addressing the risk factors or developing protective mechanisms. Both approaches are important, but for the reasons mentioned, protective mechanisms are the key to the successful adaptation of families.

There are several main reasons why emphasis on protective mechanisms is critical: protective mechanisms promote successful, healthy development throughout the lifespan regardless of risk (Werner & Smith, 1992; Rutter, 1984; Rutter, 1987); and risk factors are difficult to control. Merely knowing what the risks are does not help researchers and practitioners formulate effective solutions (Garmezy, 1989). Focusing on protective mechanisms gives health care providers a sense of hope and optimism. It has been estimated that 85% of successful change can be attributed to the positive attitude of the health care provider (Carmack, 1990). Also, the presence of protective factors guards children against negative outcomes. Even among children exposed to many risk factors, it is unusual for more than half to develop serious disability or persistent behavioural disorders when protective factors are in place (Werner, 1990). FCP is a comprehensive approach to child and family health that focuses on strengths and protective mechanisms. Thus, as most health programs place more emphasis on the risk component, there is a great

need for research and health programs to focus on FCP and its role in facilitatating the successful adaptation of all families over the lifespan.

Consumerism

Today's consumer is more sophisticated, astute, and critical than ever before. They demand services and treatments that serve their best interests and want a greater say in issues that involve them. This phenomenon has contributed to the emergence of FCP as parents have become more aware of what many knew intuitively; that their involvement with their children is beneficial for both the children and the family as a whole. Parents are demanding to be seen as more capable and intelligent than ever before, and as more than 'consultants' in their child's care. Parents are empowered when they: have access and control over the necessary resources; take control of, and responsibility for, decision making and problem solving; and acquire the means (i.e. behaviours) to do so (Dunst, Trivette, & Deal, 1988). Parents are more often considered the experts when it comes to the needs of their families and the care of their children.

One of the major outcomes of the consumerism influence is a publication entitled *Family-centered care for children with special health care needs* (Shelton, Jeppson, & Johnson, 1987). This monograph was the result of parents and professionals, brought together in the Association for the Care of Children's Health (ACCH), to define critical characteristics of the emerging concept of FCP. The work of the ACCH has stimulated professionals to examine their practices and their adequacy in promoting the concept of FCP (Jackson & Saunders, 1993). If these essential characteristics are met, families are empowered because they are treated as equal partners in their child's care and can thus take responsibility for participating in it.

Theoretical Sources of FCP

Incorporating families into the care of children has long been documented as being beneficial for both children and their families. FCP is just one approach that focuses on families as the unit of care.

History

Until the 1950's, it was commonly believed that families could only inhibit the effective care of children in hospital. Bowlby (1951) changed the perceptions of family influence on the health of sick children in his work on maternal deprivation on infants and children. He discovered that sick children actually died when deprived of interaction with their mothers. In England, 1959, the Platt Report recommended that parents should have unrestricted access to their children while in hospital and that parents should be involved when their children were admitted. It was not until 1972 that Luciano (1972a) described the philosophy of family centered care as giving recognition to the worth of the child as a member of a family and defined family centered care as an "open system extending across all hospital services, each service having a particular effect on a hospitalization experience" (Luciano, 1972b, p. 75). FCP evolved in acute care settings that had formerly required separation of infants and children from their families, and provided the family with the self-determination, autonomy, and control (Dunst, Trivette, Davis, & Cornwell, 1988) missing from earlier child health care.

It became critical to re-establish relationships between these children and their families that had been ignored or disrupted by the health care system (Broadwell Jackson & Saunders, 1993). Advances in understanding family functioning also contributed to a focus on FCP, as professionals gained greater insight into families and how to assist them in adapting successfully to various stressors. Understanding family functioning, and its relationship to adaptation, is required if health professionals are to "identify and focus accurately on the challenges seen by families as being the most important in raising their child" (Drummond, Kysela, McDonald, & Alexander, 1996, in press, p. 3).

In the United States, a series of seminars began in 1982 with "The Surgeon General's Workshop on Children with Handicaps and their Families". Then, the *Surgeon General's Report* (1987) outlined elements of family centered care along with strategies for implementing family centered interventions or individual family service plans (IFSP)

(Koop, 1987), particularly for early intervention with families of developmentally delayed children (Black, 1991). In community health settings, the concept of family centered care has been even slower to emerge, partially due to the difficulty in defining it. Yauger (1972), Porter (1979), and the ACCH (Shelton, Jeppson & Johnson, 1987) are only a few authors who have attempted to define and outline the essential components of family centered care.

Theoretical Background of FCP

The theoretical underpinnings of FCP include social systems, human ecology, and empowerment. General systems theory (GST) (Von Bertalanffy, 1968), is where the origins of modern family systems lie. There are three main assumptions of GST. First, GST recognizes "living systems as involving enormous complexities and properties that emerge from complex organization of large numbers of parts" (Whitcurch & Constantine, 1993), and that there is significant interactions between parts. Second, a system must be understood as a whole and cannot be comprehended by examining its parts in isolation from each other (Whitcurch & Constantine, 1993, p.328). In a family, the system is something beyond the parent(s) plus child(ren), and members are more than the sum of their experiences. Circular causality is also related to this assumption in that one family member influences all other family members. Third, human systems are self-reflexive (Whitcurch & Constantine, 1993), that is, they are systems with feedback due to self awareness. Families have the ability to be proactive rather than reactive; that is, to do something that will either cause change or maintain stability of the whole system, and to be aware of the consequences. Another important concept in family systems theory is that of hierarchy. Hierarchy acknowledges sytems at a variety of levels with systems smaller than the family being subsystems and those larger being suprasystems (Whitcurch & Constantine, 1993). In summary, within GST the family is viewed as an open social system with boundaries, self regulating properties, interacting and superordinate systems and subcomponents (Friedman, 1992).

Family ecology is a theory that is seen as fitting into the systems framework. Within this theory, it is proposed that families be studied as part of their ecological environment (Bronfenbrenner, 1979), with all systems being mutually interdependent (Bailey, 1987). That is, families are studied within their larger network of social and other systems. Human ecological theory also utilizes the concept of hierarchy, with the family and its immediate environment being the microsystem, and the immediate larger environment being the macrosystem (Friedman, 1992). The macrosystem also includes a community's ideology, values, and social institutions (McCubbin & Dahl, 1985). The goals of intervention, according to systems and human ecology theory, are to identify family needs, locate the resources and supports for meeting these needs, and to help families use existing capabilities and learn new skills in order to mobilize needed resources (Dunst & Trivette, 1987) within both the micro and macro systems. With the attainment of these goals, the family becomes more competent and better able to mobilize resources, which in turn leads to family empowerment (Dunst, Trivette, & Deal, 1994).

Empowerment is a controversial concept, thus it will be defined for use in this literature review. As a major focus of FCP, empowerment is the capacity of choice, which includes the "ability to define, analyze and act upon problems one experiences in relation to others, and in one's social and environmental living conditions" (Labonte, 1993, p. 101). Grace (1991) refers to empowerment as the "notion of people having power to take action to control and enhance their own lives, and the processes of enabling them to do so" (p. 330). More simply, empowerment refers to the redistribution of 'power'. When the professional has power with, as opposed to power over, the families with whom they work; and the focus is on family strengths, resilience, competence, and successes; families and children are further moved towards positive adaptation (Patterson, 1995). The three commonly accepted components of empowerment address: "access and control over needed resources; decision making and problem solving abilities; and acquisition of

instrumental behavior needed to interact effectively with others" (Dunst, Trivette, & Deal, 1988, p. 3).

Three conditions need to exist for empowerment to occur: the health care provider must believe that people are competent or have the capacity to be competent; enablement must be fostered by creating opportunities for competence to be learned or displayed; and family members must be able to attribute their behaviour change to their own actions in order to acquire the sense of control necessary to manage family affairs (Dunst, Trivette, & Deal, 1994). Unless these conditions are met, the family is unable to take control of their own affairs. Families who are empowered have the following characteristics: improved self-esteem and cultural identity; improved ability to reflect critically and to solve problems; improved ability to make choices; improved self discipline; improved ability to work with others; increased access to resources; increased collective bargaining power; and increased legitimization of the family's needs by professionals (Kindervatter, 1979). Empowering families enables them to be more confident and competent in their skills and strategies, as well as being better able to mobilize resources (Longo Kimber, in press, 1997), and address future situations. An empowered family can therefore exert influence on its environmental and social situation in a beneficial manner (Longo Kimber, in press, 1997).

Within GST and human ecology, families are positively viewed as non-static social systems with their own structures, resources, functions, and interactions (Bailey, 1987). They are capable of identifying needs, locating resources and supports for meeting these needs; and using existing strengths and learning new strategies to meet needs (Dunst & Trivette, 1987). Empowerment coincides with these views, and has been shown to have beneficial effects on families and children by enhancing their feelings of self-efficacy and personal control (Dunst, Trivette, Boyd, & Brookfield, 1994).

The philosophy behind FCP originated with consumerism, research on maternal interactions with infants, and the unique needs of the family and its members to be active participants in their own health care (Broadwell Jackson & Saunders, 1993). The

philosophy of FCP recognizes and respects the central role of the family in the lives of children with special needs (Shelton, Jeppson & Johnson, 1987). FCP is basically competency enhancing (Brinker, 1992) and empowering in that families are supported in their natural caregiving roles by building on their strengths both as individuals and as family units (Shelton, Jeppson & Johnson, 1987). Respect for the integrity and strengths of the family come through as the principle qualification of FCP (Broadwell Jackson & Saunders, 1993; Kysela, McDonald, Drummond, & Alexander, 1996), with agencies adapting services to families instead of expecting families to adapt to agency needs.

FCP focuses on family as client, as it is the main context in which children develop. The immense impact of family on a child's well-being and development has been well established (Bowlby, 1953, 1960, 1969; Brain & Maclay, 1968; Bronfenbrenner, 1974, 1986; Pasternack, 1982; Prugh, Staub, Sands, Kirschbaum, & Lenihan, 1953; Robertson, 1953; Ramey, Bryant, Wasik, Sparling, Fendt, & LaVange, 1992; Robertson & Bowlby, 1952; Shelton, Jeppson, & Johnson, 1989; Spitz, 1945), as have the benefits of family involvement in caring for sick or disabled children (Caro & Derevensky, 1991; Craig & McKay, 1958; Jackson, Bradham, & Burwell, 1978; Lewis, Salas, de la Sota, Chiofalo, & Leake, 1990; Verghese, 1988; Weinstein, Faust, Mckee, & Padman, 1992; Yauger, 1972), and benefits to the health care system (Caldwell & Lockhart, 1981; Evans & Robinson, 1983; Robinson, Shah, Argue, Kinnis, & Israels, 1969; Sainsbury, Gray, Cleary, Davies, & Rowlandson, 1986; Vermillion, Ballantine, & Grosfield, 1979). Therefore, as FCP focuses on the family, and aims at strengthening and building family resources, it is one approach for practitioners to effectively and postively influence child development.

Components and Criteria of FCP

FCP is described as an approach to care that is "tailored to meet the special, intricate, and ever-changing needs of all family members, not just the needs of an individual child within the family" (Broadwell Jackson & Saunders, 1993, p. 33).

Comprehensive care of children with special needs necessitates family centered care. Each family's uniqueness is recognized and interventions planned in conjunction with the family accordingly (Bailey & Simeonsson, 1988; Vincent, 1992). FCP allows families to participate together in a variety of settings, from the hospital to the home (Broadwell Jackson & Saunders, 1993), as well as providing for a wide range of professionals who can interact with the family. FCP is ultimately aimed at building and supporting the stability and strengths of the family. The four main goals of FCP are described as incorporating family coping; understanding child development; promoting appropriate parent-child interactions; and encouraging parents to be equal partners in the assessment, planning, implementation, and evaluation of intervention (Bailey & Simeonsson, 1988).

Several authors (Bailey, Buysee, Edmondson, & Smith, 1992; Dunst, Johnson, Trivette, & Hamby, 1991; Lee, 1993; McBride, Brotherson, Joanning, Whiddon, & Demitt, 1993; Shelton, Jeppson, & Johnson, 1987, 1989, 1992; & Shelton & Stepanek, 1994) have outlined the characteristics of family centered care, and in 1994, the ACCH published an updated and comprehensive version of what are now commonly considered the eight essential principles of family centered care. The Izaak Walton Killam Chilren's Hospital Family Centered Care Committe (1992), as cited in Bruce (1992), also added a ninth criteria of implementing appropriate policies and programs and providing emotional support to meet the needs of staff (Appendix A). These essential principles share some commonalities with those of other authors: 1) an effort to fully involve families in active decision making regarding their, and their child's, care; 2) development of services for the entire family, not just the child; 3) involvement of families in program planning and service delivery; and 4) the family's choices regarding their level of participation is respected. A fifth common criteria recognizes the parents as experts with regards to their family's needs and priorities (Kysela, McDonald, Drummond, & Alexander, 1996). These five criteria will be utilized in this research to define and evaluate FCP (Appendix B). Although the effects of parental and family involvement in the care of children have been documented, it

is not until recently that similarities and differences in application of the principles have been studied to delineate specific approaches. That is, simply involving families in the care of their children is not enough to be considered FCP.

Most of the components of family centered care and FCP have been developed into measurements. That is, there are instruments available to evaluate whether approaches are family centered, with assessment varying depending on the criteria used. However, until recently little attention has been paid to helping health care providers to operationalize the principles of family centered care or FCP through their work. It seems only logical that if there are criteria to measure FCP approaches, that there be approaches to measure.

Measurement of Family Centered Practice

As FCP evolved, and the principles of FCP began to be applied in practice, academics and practitioners were obligated to measure it. This process is somewhat backwards in that there were more measurements than documented approaches. That said, there are several tools available to assist in measuring FCP, with some being better than others. For practical purposes, this review will cover only two tools. A critique of both tools will be included in this discussion. The five FCP principles were deemed adequate and appropriate to be used in the evaluation of the approaches of interest in this study. Although neither of the tools were utilized in this study, they are worth noting. The first tool is the Measure of Processes of Care (MPOC), developed by King, Rosenbaum & King (1995). This tool is a five scale, 56 item, self-administered questionnaire for parents. The items focus on actions or behaviours of health professionals or treatment centre staff from the parents' perspectives. Parents use a seven-point response option to record their answers to questions of "To what extent" does a particular behaviour happen. The MPOC has undergone extensive development and testing to determine its reliability and validity, and to provide evidence of its psychometric properties. Ongoing work is currently being done to further the reliability and validity of the MPOC over time as well as with various populations. Each scale has been found to have high internal consistency (Cronbach's

alpha ranged from 0.81 to 0.96), good test-re-test reliability (intra-class correlation coefficients for the scales ranged from 0.77 to 0.88), and scores are significantly correlated with a standardized measure of satisfaction, the Client Satisfaction Questionnaire (Larsen, Attkisson, Hargreaves, & Nguyen, 1979). The MPOC is a comprehensive measure of parents' perceptions of the care they and their children receive, and assesses the extent to which health care providers and institutions engage in family centered behaviours. MPOC measures the way in which care is delivered and the impact that this care has on children with disabilities and their families. In keeping with the principals of FCP, development of MPOC included piloting, field tests and focus groups with families of children with disabilities. Although lengthy, this measure is an easy pencil and paper questionnaire to complete. MPOC is beneficial to practitioners and researchers interested in FCP as it gets to the process (i.e., what is done and how it is done) of care-giving in a family centered way, particularly as experienced by parents. MPOC is a useful tool for planning and evaluating programs; staff evaluation and research.

The second tool to be reviewed is the Family-Centered Program Rating Scale (FamPRS) (Murphy, Lee, Turnbull, & Turbiville, 1995). FamPRS is a paper and pencil rating scale completed by both parents and staff, designed to be used in the evaluation of programs serving young children with disabilities, aged birth through five years, and their families. It consists of 59 items with 11 subscales: flexibility and innovation in programming; providing and coordinating responsive services; individualizing services and ways of handling complaints; providing appropriate and practical information; communication timing and style; developing and maintaining comfortable relationships; building family/staff collaboration; respecting the family as decision-maker; respecting the family's expertise and strengths; recognizing the family's need for autonomy; and building positive experiences. FamPRS assesses the role of parents in their child's services, in family services, and in policies and systems in both quality and importance. The items describe family-centered practices, and ratings provide information about the degree to

which these programs are family-centered. Results may be used as a tool for program planning, evaluation, staff development, and research. The subscales of the FamPRS have shown high reliability in a national field test. For parents, coefficient alphas ranged from 0.71 to 0.87, with a mean of 0.79; and for staff, 0.63 to 0.87, with a mean of 0.74. To ensure the content validity of the tool, expert judgement was solicited from several key sources, both parents and professionals. Evidence of construct validity is derived mostly from the results of the principal components analyses and reliability analyses. Studies are ongoing to collect evidence of reliability and validity.

As with MPOC, FamPRS provides practitioners and researchers with a comprehensive measure of a program's 'family centeredness'. This tool is based on a definition of FCP which is essentially that used by the ACCH (Shelton & Stepanek, 1995), and is supported by theory. FamPRS also focuses on the fact that families are of great importance in the lives of children. FamPRS, like MPOC, also was developed with input from families of children with disabilities. FamPRS, too, is a useful tool for planning and evaluating programs, and staff development.

One point to be aware of in using these tools, is that they measure individual level data, with input being solicited from the parents, and generalized to the family. This is a controversial issue in family research (Kristjanson, 1992; Lobo, 1986; McCubbin, McCubbin, Thompson, & Huang, 1989; Murphy, Lee, Turnbull & Turbinville, 1995), however, it is generally accepted that family information in certain instances (i.e., young children and other subjects who are unable to speak for themselves), is obtained from the mother (Lobo, 1986) and/or other primary caregiver(s). Murphy, Lee, Turnbull, & Turbinville (1995) specifically address this issue by stating that they intended to develop a tool to measure parents' perspectives on programs for their families and child with special needs, and that they used "parents' perspectives as the standard for judging a programs performance" (p. 33). The issue is acknowledged, and the investigator believes that it is possible to obtain useful information regarding families from primary caregivers. It is

suggested that consumers of research note this issue, come to their own conclusion regarding family level data; read research results closely, and regard the interpretations with caution.

In general, the tools reviewed here are not sufficient to operationalize the entire process of FCP, which is not their intent. Used in conjunction with each other, and perhaps other tools, these tools provide a fairly comprehensive measurement of the FCP process (i.e., assessment of families, staff behaviours and programs/institutions) according to the key principles of FCP (IWK Family Centered Care Committee, 1992; Shelton & Stepanek, 1995). Both tools are user-friendly with simple instructions and lay language, and offer specific approaches to evaluating family centered programs that are more detailed than the FCP principles. These tools also acknowledge the importance of family in the lives of children, and address parents' needs and concerns, which fits with FCP (i.e., that is when the children are too young or otherwise unable to provide input) and the current emphasis on consumerism. As researchers have discovered, FCP principles and measurements are in place, leaving a need for specific approaches.

Family Centered Approaches

FCP has been documented as being beneficial in many ways, yet there are barriers to its implementation in practice. The FCP studies reviewed all incorporated elements of FCP, however, none explicitly defined approaches as FCP; with the exception of Drummond, Kysela, Alexander, McDonald, & Query (1996). Barriers to implementing FCP include education and knowledge level of staff, perceptions of staff, staff position and availability, organizational environment, role negotiation and communication, parental and marital status, and costs (Letourneau, 1994). Education and knowledge level of staff have been shown to be positively related to their perceptions of FCP, which in turn, is positively related to staff practicing FCP. Studies show that not all health professionals value FCP equally, and that those who put less value on it, offer it infrequently (Knafl, Cavallari, & Dixon, 1988; Rosenbaum, King, & Cadman, 1992). Staff position and experience (Dunn,

1979; Gill, 1987; Porter, 1979; Siedl, 1969; Bailey, Buysse, Smith, & Elam, 1992; Letourneau, 1994), age (Dunn, 1979; Letourneau, 1994), organizational setting (Bailey, Buysee, Edmondson, & Smith, 1992; Gill, 1987; Knafl, Cavallari, & Dixon, 1988; Porter, 1979; Siedl, 1969; Thornes, 1983, 1985), as well as parental and marital status of health care professionals (Gill, 1987; Porter, 1979) all influenced the value professionals placed on FCP.

However, those who perceive FCP as being beneficial and agree with the essential principles of FCP do not necessarily practice accordingly. Focus on the child (Knafl, Cavallari, & Dixon, 1988), role discrepancies (Algren, 1985; Berman, 1991; Bruce, 1992; Porter, 1979), differences in perceptions of ability of parents (Thornes, 1985; Webb, Hull, & Madeley, 1985) and staff (Bailey, Palsha, & Simeonsson,1990; Brown & Ritchie, 1989, 1990), time and availability of staff to parents (Callery & Smith, 1991; Hayes & Knox, 1984; Mahoney & O'Sullivan, 1990; Ogilvie, 1990; Park, 1991; Humphry, Gonzalez, & Taylor, 1993), level of education and knowledge level of FCP (Dunn, 1979; Gill, 1987; Humphry, Gonzalez, & Taylor, 1993; Letourneau, 1994; Porter, 1979; Siedl, 1969), and cost (Mahoney, O'Sullivan, & Dennebaum, 1990) are cited in the research as reasons for the discrepancy between beliefs and practice. Knowledge level of FCP is also directly related to educational curricula in professional programs (Cochrane, Farley, & Wilhelm, 1990; Bailey, Simensson, Yoder, & Huntington, 1990), and to the profession of which the practitioner is a member (Bailey, Palsha, & Simeonsson, 1990; Letourneau, 1994; Marvel & Morphew, 1993; Porter, 1979). These studies also identify a communication gap between families and staff as being a barrier to implementing FCP. I would also put forward the reason that there is not enough practical information (i.e. specific approaches), backed by research, in order for practitioners to implement FCP.

Due to mixed findings regarding FCP approaches and uneven application of FCP principles, the Centre for Research in Applied Measurement and Evaluation at the University of Alberta developed two interventions to meet the demand for family centered

approaches. It is becoming clearer to researchers and practitioners that more developed approaches, rather than criteria and principles, are necessary to facilitate implementation of FCP. These recently developed interventions, reported as being family centered, were implemented in a larger study, and are currently undergoing further testing. The interventions were each paired with Family Centered Assessment, an approach developed to assist practitioners in finding out where families are 'at' in terms of functioning prior to implementing interventions. The Family Centered Assessment is not a focus for this study, but will be reviewed to put the interventions in context. The two interventions are Cooperative Family Learning (CFL), and Natural Teaching Strategies (NTS), and were developed within the framework of the Family Adaptation Model (FAM) (Kysela, McDonald, Drummond, & Alexander, 1996). The model and the two interventions are based on ecological theory, family systems theory and empowerment, all of which relate back to the theoretical underpinnings of FCP. The model is based on characteristics of resilient families and was developed to assess family functioning in those areas. FAM incorporates the three elements of demands, supports and coping strategies. In assisting the family to adapt, we are also assisting in the development of their capacity to be resilient in the face of other risk factors either within the environment or within the family unit (Alexander, Kysela, McDonald, & Drummond, 1996).

Family Centered Assessment (FCA). FCA utilizes a combination of tools, one of which is the Family Profile, a structured tool to assist in the assessment of where the family is at in terms of: appraisals (meaning of life and situational events); pile-up of demands and stressors; family adaptation (general protective factors); problem solving and coping; and support (community and family resources). Bailey and Simeonsson (1988) suggest that family assessment is more effective when family centered practices are incorporated. This type of assessment assists health care providers by providing a model for organizing and interpreting information about a family's strengths, needs, priorites and skills so that intervention can be tailored to each individual family system as Individualized Family

Plans. The information gathered from the profile is also useful in summarizing information gathered from formal assessments, and in documenting change in the family (Alexander, Kysela, McDonald, & Drummond, 1996) system. The purpose of the assessment is to identify the tasks and information with which the family members may be having difficulty, and to assist them in identify the resources available to assist them in dealing with their struggles (Alexander, Kysela, McDonald, & Drummond, 1996).

The profile is a written survey that parents fill out regarding their particular families, that is supplemented with observation and other conversation. Parents are able to write down their own strengths, stressors, resources and perceptions in a way that parallels the model used by the original researchers (Family Adaptation Model (FAM), Alexander, Kysela, McDonald, & Drummond, 1996). Assessment of families is an integral and ongoing part of early intervention that evolves and changes as families' needs change and professionals better understand the dynamics of a specific family system (Alexander, Kysela, McDonald, & Drummond, 1996). Once families and practitioners have identified areas of strengths and needs and priorized their goals, a specific plan or intervention can be selected. Cooperative Family Learning and Natural Teaching Strategies are both ways of moving beyond the initial assessment. These interventions have a different focus but both are reported as valuing and encouraging togetherness, communication and family time which are important factors in developing strong, resilient families. The interventions can be used together, with other interventions, or separately depending on the family's major need (Alexander, Kysela, McDonald, & Drummond, 1996). Both interventions focus on the positive in that the family's strengths and capabilities are emphasized, rather than weaknesses and limitations; as well as various aspects of the six essential patterns of behaviour that offer protection for child health. The six elements are: flexibility; stability in structure; family problem solving; effective parenting; social support networks; and links with the community (Drummond, Kysela, Alexander, McDonald, & Query, 1996).

Cooperative Family Learning (Drummond, Kysela, McDonald, Alexander & Shank, 1996). CFL is based on an original approach developed by Shank (1991) and aims to increase the following specific factors in children and families. In the child, cognitive cooperative learning skills; positive self-esteem and efficacy; and mastery behaviours are emphasized. In the family, effective parenting; good family coping strategies; good family cooperative learning strategies; supportive spouse; enhanced parental self-esteem; and stronger support network within and beyond the family are emphasized (Alexander, Kysela, McDonald, & Drummond, 1996). The main objective of CFL is to support coherence in families' responses to crisis; and to provide the opportunity for families to learn skills that they can apply to all family issues.

CFL is a modification of Shank's Cooperative Learning (CL) approach. CFL includes all family members and not just parents in order to make the process truly family focussed, whereas, Shank's approach did not include all family members. CFL is based on research literature that has identified twelve steps in situational cooperative learning. The reader is referred to the literature on co-operative learning for further discussion of the twelve steps. The twelve steps were combined with a CL model developed by Johnson and Johnson (1975). The model was developed for teachers to use in structuring lessons to enable their students to work together and attain common goals (Johnson, Johnson, Holubec, & Roy, 1984). CL is based on the assumption that because "positive interdependence exists among students' goal attainments, students seek outcomes that are beneficial to all individuals with whom they are linked cooperatively" (Shank, 1991, p. 43). CL became CFL when all family members were included.

There are four levels of cooperative skills in CFL that must be mastered in succession. CFL and CL also incorporate a 'WE CAN' strategy that utilizes CL approaches with families of children with special needs/disabilities and practitioners to enhance problem solving skills. The approach uses the acronym -WE CAN- to operationalize the phases of family problem solving. The component skills required for

successful CL were more completely outlined and strategies for their development were designed. The motto WE HAVE THE SKILL describes these skills and expands on Shank's (1991) WE CAN acronym. The goal of CFL is to improve generation of solutions and cooperation in families. Problems are viewed as opportunities to learn and are positively described as 'situations'. The emphasis is on agreement and compromise rather than agreement to disagree. The WE CAN was originally designed for use in group sessions, but has been modified for use with families on an individual basis in the more naturalistic setting of the home. The CFL has also been modified to take place over twelve weeks as opposed to five (Alexander, Kysela, McDonald, & Drummond, 1996).

Natural Teaching Strategies. (McDonald, Alexander, Kysela & Drummond, 1996). NTS was designed to influence effective parenting and aims to increase the following specific factors in children and families. In the child, social competence and social and interpersonal skills; mastery behaviours; communication competencies; and cognitive competencies are emphasized. While in the family, positive parent-child interactions; structure within the household; and positive communication are emphasized. These techniques are widely believed to be effective in enhancing child development and are *natural* in the sense that most parents have used these techniques at one time or another in everyday situations, without prompting or specific education. Like CFL, NTS looks at family situations as opportunities to learn.

The specific phases of NTS are: Following your child's lead: Turn taking through imitation; Keeping the action going; Expansion-Adding something more; Incidental teaching; and, A new look at challenging behaviour. Each of the phases will be described here briefly. Interventionists consistently model the phases in their interactions with parents and families. Time spent on each phase depends on the parents' familiarity with that phase, as well as readiness and willingness to continue.

Following your child's lead: Turn taking through imitation is the first phase and encourages parents to listen to their child(ren) and to observe them. The idea that all

behaviour does communicate is reinforced; and parents are encouraged to imitate, sustain, and keep a conversation with their child(ren) going in a 'give and take' fashion by taking turns. The second phase, Keeping the action going, looks at ways the parents can keep a child involved for a longer period of time by balancing turns and following the child's lead. The third phase, Expansion, is intended to add something more to their conversations to make them more interesting. Expansion involves three steps: 1) Identify the child's level of communication; 2) Wait, signal, and prompt for a turn, and 3) Imitate the child's level of communication and model a better turn at the child's level or model a turn one step higher.

Incidental teaching, the fifth phase, focuses on teaching children other skills besides language using strategies parents have already learned like modeling and prompting. Modelling involves demonstrating the behaviour you want imitated in a clear and simple manner. Prompting is used when imitation does not come naturally to a child and involves a 'Tell, Show and Do' chain. Prompting is used as little as possible as it does not allow the child to learn how to be in control. The sixth phase, Challenging behaviour, stresses that all children 'misbehave' or do things parents do not like, but it is unlikely that the child is deliberately trying to annoy their parents; and that all behaviours have meaning. Parents are encouraged to interpret the message their child is sending by finding the meaning behind the behaviour (e.g., tantrums while shopping are related to being hungry, tired, or not feeling well).

It is believed that by using the techniques of NTS consciously and selectively, they will have a positive effect on parent-child interactions and on child development. The strategies are based on research literature in the areas of education and language development. The goal of NTS is for parents to develop a better understanding of how to initiate, sustain and extend their child's interactional/interpersonal skills, and how to do it while having fun. NTS are designed to be used in a variety of different settings and for any situation that might arise within the family.

## Conclusion

It has been well documented that FCP is beneficial to the entire family system of children with special needs, as well as to the children themselves. One area in particular that benefits from FCP is family adaptation. The literature contains descriptions of criteria and components that constitute FCP and measurements to evaluate FCP approaches; yet specific FCP approaches, and their utilization, have not been well documented. Past research has also shown that practitioners are not implementing FCP, even though research results have been conclusive with regards to its beneficial aspects for families. Furthermore, FCP with at-risk families of children with mild to moderate developmental delay has not been explored adequately in the literature to any extent. The need for adeqate descriptions of the process is essential to: establish a solid base for further study; direct practice; plan effective programs; and educate those involved (or who wish to be involved) in FCP.

# Chapter 3

## Research Methods

### Design

A qualitative descriptive design using review of documents, semistructured interviews, and electronic mail (e-mail) questionnaires was used to answer the research questions. A single application of open ended questions was utilized in both the interviews and the questionnaires to draw out the process of implementing family centered practice via two specific interventions (i.e., NTS and CFL), and the 'family centeredness' of the interventions. A descriptive design is an appropriate level of design as little is known about implementing and experiencing family centered practice.

### Sample

The convenience sample used in this study was composed of those past-participants of the original study (i.e., during 1995/1996) who gave their consent to take part in the current study. Participants were subdivided into three categories: families, interventionists, and researchers. Sub-samples were identified based on roles in the original study. The sample of families was composed of those phoned by a third party associated with the original research project; who agreed to be contacted by the researcher; and who consented to participate in the study. Interviews were then conducted in person with the family member(s) who participated in the original research. All of the families identified who met the criterion for entrance to the study were interviewed. Criteria for entrance to this study included:

1) Participation in the original study (received one or both interventions), and met the original study's criteria (had a pre-school child aged three to six years enrolled in ABC Headstart; the child had to show a six month or more delay in two or more areas; and the family needed to report the presence of two or more family risk factors-parental education less than grade 10, family income less than $20,000 per year; divorced or lone parent status, and substance or other abuse practices).

2) Family data sets included the information to be reviewed.

3) Family lived in the greater city area.

4) Family had a telephone or was otherwise accessible.

5) Family member(s) interviewed had reasonable (i.e., no translator required) English language skills.

The interventionists and researchers, at the time of the original study, worked under the auspices of the Center for Research in Applied Measurement (CRAME) at the University of Alberta. The interventionists assessed the families and implemented the interventions in the original study. The researchers developed and managed the interventions used in the original study, educated the interventionists in their use, and directed the interventionists in their implementation. The only criteria for entrance to this study for these two sub-samples were that they consent to participate, and either live in the greater city area, or have access to e-mail. Finally, while not a criterion for entry into the study for the interventionists and researchers, it can be assumed that those who responded to the e-mail questionnaire could read and write English.

Data Collection Procedure

The following data collection methods were utilized to collect data for analysis in this study: researcher diary, demographic questionaires, review of documents, semistructured interviews, and e-mail questionnaires. Permission was granted by the original research team to access data from their study (Appendix C).

New data included: demographic data for families, researchers, and interventionists; and information gathered from the family interviews and from e-mail questionnaires sent to the researchers and interventionists. The data utilized for secondary analysis were: the independent variable schedule for NTS and CFL (Appendix D), the intervention manuals, as well as the family satisfaction surveys (Appendix E) and the interventionists' notes for the families who consented to be interviewed. Summaries of the data collected from the families were included in questionnaires e-mailed to the

interventionists. Subsequent questionnaires e-mailed to the researchers included the summarized family data as well as that of the interventionists. All participants were provided the option of receiving a copy of the results of this study.

A member of the original research team, who had access to the family data but did not know who the families were aside from their name and telephone number, contacted families whose data sets were complete by telephone to determine their willingness to participate in this research. The purpose of this contact was to provide potential family participants with information regarding the purpose of this study, should they consent; to confirm their residence; and to get information about family times available. The original research study was referred to as the 'home visiting study' in any written or verbal communication with the families. The investigator provided the particulars of participation upon her initial telephone contact with the family, and at the interview. Appendix F contains the correspondence used with/sent to participants.

The investigator was given the names of only the families who gave permission to be contacted. Of all families contacted by the third party, only three consented to be interviewed. There was no record of the number of families contacted, or of those who declined to participate in this study. The investigator then set up an interview with them as soon as possible to prevent losing contact. Demographic data were collected, and the information letter and consent reviewed with the family, at the interview. At the end of the interview the family was left with a Request for Results card to return, if they so chose, at their earliest convenience. Interviews were taped, with the participant's knowledge and consent, and transcribed for analysis. Families were given the option to forgo audiotaping for detailed note taking if they objected to being taped. All families interviewed agreed to be audiotaped. The families were contacted by telephone after their interview was transcribed and analyzed for both clarification and verification.

Data gathered from the family interviews were used to compose portions of the questionnaires intended for the interventionists and researchers (separate questionnaires).

Data from the interventionists were also utilized for the researchers' questionnaire. Initially, an information letter and demographic questionnaire were e-mailed to the interventionists and researchers. Questionnaires, accompanied by a Request for Results form, were also sent via e-mail to all participating interventionists and researchers. Returning the questionnaire indicated their consent to participate. There was one exception, in that one of the researchers preferred to be interviewed, and the same process was followed as for the families. All of the interventionists and researchers participated in this study. Also, in order to maintain awareness of personal biases and interpretations, the investigator kept a research diary.

Instrumentation

In qualitative research, the researcher is considered an instrument, and the information gathered from the interview depends on the ability of the researcher to establish rapport and gain informants' trust (Morse & Field, 1995). This was of particular importance as family participants were from vulnerable populations. The investigator made every attempt to ensure her demeanor (i.e., verbal and body language) and dress was neither intimidating nor insulting; and sought input on the family interview questions from a panel of experts, in order to determine their appropriateness for the population.

The questions used in the family interview, and the questionnaires for the interventionists and researcher, were designed specifically for this study and based on the literature review and consultation with persons experienced in the areas of vulnerable populations, families of children with developmental disabilities, and qualitative research. Questions for families, interventionists, and researchers included those that pertained to their demographic characteristics, past/present situations, satisfaction and experience with the interventions, as well as the family centeredness of the interventions. The concluding question for both the interviews and the questionnaires, was in regards to 'anything else (the participant) would like to say about the interventions, the interventionists, or...'. The

interventionists and researchers were also questionned regarding their knowledge level of FCP. Interview questions and e-mail questionnaires are located in Appendix F.

Participant Characteristics. Family, interventionist, and researcher characteristics were established through demographic questions. Demographic data collected from the families was the same as that collected in the original study for purposes of comparing families.

Questions Pertaining to Past/Present Situation. Open ended questions were used to determine what, if anything, had changed for the families, researchers, and interventionists since completion of the original study. These questions were necessary to determine potential influencing factors in participants' reported behaviours and experiences.

Experience of the Families, Interventionists, and Researchers With the Interventions. Participants' experiences were accessed by using open ended questions based on predetermined catergories of interest in this study: satisfaction (adapted from original study's satisfaction survey), sustainability, FCP principles, facilitating factors and barriers to FCP.

Family Centeredness. To assess participants' perceptions regarding the family centeredness of the interventions, open ended questions relating to the principles of FCP were used; along with asking outright about the presence or absence of same principles were used.

Knowledge level of FCP (Interventionists and Researchers). Knowledge level of FCP was ascertained through the use of open ended questions regarding knowledge prior to participating in the study, education/training relating to FCP, and perceptions of FCP.

Research Standards

The literature contains an extensive and ongoing discussion about the standards for qualitative research (Brink, 1991; Morse & Field, 1995: Goetz & LeCompte, 1984; Howe & Eisenhart, 1990; Phillips, 1987; Robinson & Thorne, 1988; Sandelowski, 1986; Strauss & Corbin, 1990; Yonge & Stewin, 1988). These discussions are of two different veins:

using the language and standards of quantitative research such as reliability and validity, or developing and utilizing standards specific to qualitative research. Although it is imperative that quality be maintained in qualitative research, researchers are becoming increasingly aware that quantitative research standards are inadequate for assessing the merit of qualitative research (Howe & Eisenhart, 1990; Phillips, 1987; Sandelowski, 1986; Strauss & Corbin, 1990).

Various authors suggest that the notion of reliability and validity in quantitative and qualitative research be replaced with the notion of standards, or rigor. Lincoln and Guba (1985) outline four general criteria for evaluating qualitative research: truth value or credibility, applicability, consistency, and neutrality or confirmalbility. They believe these criteria to be relevant to both qualitative and quantitative research. Similarily, Howe and Eisenhart (1990) outline four criteria by which to evalutate qualitative research that are discussed as they relate to the limitations and strengths of this study:

1) and 2) Fit and Competence of Data Collection and Analysis: Collection and analysis procedures should be compatible with and be driven by the research questions; and competence in tool development, data collection techniques and methods of analysis must be ascertained. In this study, the match between the research questions, methods, and analysis, along with deliberate scheduling, and cascade of data analysis (See Table 1) was made as harmonious as possible given the skill level of the researcher. The interview questions were reviewed by a panel of experts to ascertain their appropriateness for the populations, and their effectiveness in answering the research questions.

3) Credibilty: To determine whether warranted conclusions were drawn based on: a comparison with the literature; background assumptions congruent with the research questions and methods; revelation of researcher subjectivities; the identifiable ability of the researcher to be "alert to and being able to employ knowledge from outside the particular perspective and tradition within which one is working, and being able to apply general principles for evaluating arguments" (Howe & Eisenhart, p. 7); and, the data. Another

aspect of credibility is audibility. Audibility is "achieved when the researcher leaves a clear decision trail concerning the study from its beginning to its end" (Sandelowski, 1986, p. 34). The researcher's logic, problem solving and desision making is made clear to the reader via documentation of these processes.

In this study, credibility was ensured by the research team being composed of a neophyte researcher, as well as an experienced and doctorally-prepared researcher familiar with the field of study. The undertaking of this study was supported in the literature, and results from this study are discussed in relation to the literature. As well, the researcher maintained a strict audit trail consiting of a researcher diary where decisions, choices, and insights were recorded. In addition to these efforts, the researcher incorporated multiple sources of data to assess for similarities and differences among the various sources.

4) Value Constraints: External value constraints refer to the worth, in terms of practical significance, of the research. This includes the dissemination of findings in appropriate forms to relevant individuals or groups. Internal value constraints refer to ethical issues. Protection of participants may take priority over the collection or analysis of data that would increase warrant by substantiating the conclusions drawn (Ogilvie, 1993). In this study, the criteria of value constraints was met through the practical significance of this research to various audiences, and the attention paid to ethical considerations. These four criteria are consistent with Morse and Field's (1995) discussion of rigor in qualitative research.

Final Data Analysis

The approach to data analysis for a qualitative descriptive study was based on Morse and Field (1995). There were four types of data analysis carried out in this project: descriptive statistics, content analysis by pre-established themes, comparative analysis of text, and summary analysis of text. These are addressed generally here, while Table 1 outlines how they relate to the research questions and data sources in this study.

1) Descriptive statistics refer to the sample characteristics, and how they are numerically described (for example, mean, median, mode, etc.). In this study, the descriptive statistics were calculated from nominal and ordinal data gathered from the demographic profiles of all participants, and the family satisfaction surveys completed for the original study.

2) Content analysis is one method by which qualitative data may be structured to enhance analysis by transforming the symbolic content of a document, such as words, into a systematic form (Holsti, 1968; Krippendorff, 1980; Weber, 1985). This method of analysis employs coding, which refers to the categorizing of behaviours or elements into a limited number of categories, to quantify verbal or symbolic content. Content analysis by pre-established coding themes was used in this study in order to partially answer the second and third research questions. This is possible as there are categories determined by the purpose of this study: sustainability, satisfaction, FCP principles, and facilitating factors and barriers for FCP. That said, the researcher also remained open to additional categories as they may have emerged from the data.

Responses to interview questions and the questionnaires were sorted into categories and defined by the principal investigator. Summaries of the family interview data were taken back to each family for verification and clarification as necessary. Interventionist and researcher responses were not verified as their responses were straightforward and sorted essentially by question.

3) Comparative analysis of text in this research essentially refers to using one written document as a referent and comparing another to it, without interpretation. In order to answer the first research question, the independent variable schedule was the referent for the interventionists' notes, and the five FCP principles were the referents for the interventionists' notes and the intervention manuals.

4) Summary analysis of text refers to a brief written description without interpretation, of written documents in order to provide data for the family interviews, and the interventionist and researcher questionnaires. To assist in answering the third research question,

aggregate summaries of the family interviews were provided to the interventionists; then, those summaries, along with a summary of the interventionists' data, were presented to the researchers from the original study.

In addition, descriptive statistics were used to describe the demographic characteristics of the families, interventionists, and researchers. These data do not address any particular research question, but give the reader a 'picture' of the samples, and allowed this researcher to compare profiles of the families in this project with the profiles of the original study's sample. Upon completion of these analyses, the content analyses from all three participant groups were compared; conclusions of the interventionists and researchers expanded, and further implications drawn for the interventions and FCP based on these data. Results of this study were taken back to the literature and discussed according to the findings thereof.

Table 1

Summary of Data Analysis

| Question | Data Source | Analysis Technique |
|---|---|---|
| 1) How was FCP implemented in the original study? | interventionist manuals | 1a) comparative analysis to principles of FCP |
| | independent variable schedule | 1b) comparative analysis (to principles of FCP and to interventionist notes) |
| | interventionist notes | 1c) summary analysis |
| 2) How was FCP experienced by families in the original study? | survey | 2a) summarize Likert outcomes to compare study results with original aggregate data |
| | interview (uses 1c and 2a) | 2b) content analysis using pre-established categories (satisfaction, sustainability, FCP principles, facilitating factors and barriers to FCP), and remaining open to categories that may have emerged. |

(table continues)

| Question | Data Source | Analysis Technique |
|---|---|---|
| 3) How do the facts of implementation of FCP, in conjunction with the participants' reported experiences, inform understanding of FCP? | e-mail questionnaires for interventionists and researchers (plus one in person interview with one of the researchers).<br>- used aggregate summary of family interviews (from 2b)<br>- content analysis of interventionists' questionnaires (3a) will be used in researchers' questionnaire | 3a) content analysis using preestablished categories as for question number 2, and remained open to categories that may have emerged.<br>3b) comparison of analyses of all 3 participant groups. |

Protection of Human Subjects

Protection of human subjects was ensured in a number of ways. The approval of the University of Alberta Ethics Review Committee for Health Sciences Research was sought prior to any contact with participants (Appendix G). All written descriptions of the study were confirmed to be at or below a grade nine reading level and in a format which made them easy to read. Grade levels were determined by the Flesch-Kincaid Readability Scale. This program uses syllables/word, and words/sentence to calculate a grade level. However, after being run with various word processing programs, the results were inaccurate and read higher than they should due to the small sample size (i.e., of sentences), and the inability of the program to 'read' the point form format. A panel of experts was consulted in developing, and the ethics committee approved, the final drafts of the information letters and consents. All subjects were told their participation was

voluntary and that they were not obligated to answer all questions. The city of location of the study will not be published or included in this thesis and related presentations. Written consent was obtained from the families and one researcher who were interviewed, while return of the e-mail questionnaires implied consent to participate for the interventionists and the remaining researchers.

Confidentiality was maintained by identifying questionnaires, transcripts, and other documents and reports by codes, not names; and aggregate data are reported. Participants were assured that this thesis, and any reports, publications or presentations would not reveal their personal identity. Data from this study may be used in secondary analysis only if approval is received from the appropriate ethical review committee. Data are stored under lock and key, accessible only to the researcher, while identifying data are locked in a separate cabinet. The information gathered is to be kept for at least seven years after this study is finished, and the consent forms are to be kept for at least five years. Family participants were offered the opportunity to forgo taping of interviews for detailed note taking in order to reduce any real or perceived threat to them in reporting personal and sensitive information.

Only those families who agreed to be contacted by the researcher were known to the researcher. The researcher had access to data for only those families who gave their consent to be interviewed. Participants were informed of the following: they had the right to withdraw from the study at any time with no consequence to them, and information previously revealed would be removed from analysis on their request. Sensitive information would be reported only with the explicit consent of the participant. Data were pooled or disguised in order to protect the identity of the participants. Anonymity for the families was also protected by not discussing the names of participants by either myself or the member of the original research team who initially contacted them. Anonymity for the researchers and interventionists could not be guaranteed due to the small numbers of them, and the fact that they all have worked, and some are currently working, very closely with

each other. It was determined that there were no identifiable risks to participants for taking part in the study. Confidentiality was addressed by 'researcher only' access to individual participant data. The potential participants were given the name of the Associate Dean of Research in the Faculty of Nursing at the University of Alberta, who was not associated with the researcher or the study, to contact if they had any questions or concerns about this study.

# Chapter 4

## Results

In this chapter the demographic data of the family respondents and of the interventionists and researchers are presented. The results of the study follow and are organized according to each research question. First, the participant characteristics are described and family data are compared to the demographic data collected in the original study. Second, the implementation of FCP in the original study is described. This description is followed by summaries of how FCP was experienced by families in the original study. Finally, summaries of the interventionists' and researchers' reported experiences and observations are presented.

### Demographics

Demographic data was collected from the families via a questionnaire administered at the beginning of the interview. Of all families contacted, only three consented to participate in this study. It is not known how many families were contacted, or how many declined to take part in this study. In Table 2 and Table 3 the data is displayed for primary care-givers and for children in this study as well as the original study. The interventionists and researchers reported demographic data by email. Tables 4 and 5 depict this data respectively.

Table 2

Primary Caregiver's Age, Gender, Cultural Background, Education Level, Occupation, Marital Status, and Family Income

| Characteristic | Frequency | |
|---|---|---|
| | This study, n=3 | Original Study |
| Age | | data unavailable |
| Under 20 years | | |
| 20-25 years | | |
| 26-30 years | 1 | |
| 31-35 years | 1 | |
| 36-40 years | 1 | |
| Over 40 years | | |
| Gender | | data unavailable |
| Male | | |
| Female | 3 | |
| Cultural Background (self-identified) | | data unavailable |
| Spanish | 1 | |
| German/Irish | 1 | |
| Lebanese | 1 | |
| Education* | | |
| Less than seven years | | 2 |
| Junior High | 2 | 6 |
| Some Senior High | 1 | 16 |
| High School | | 16 |
| Some College | | 4 |

(table continues)

| Characteristic | This study, n=3 | Original Study |
|---|---|---|
| College/University | | 1 |
| Diploma/Technical Training | | |
| Occupation[a] | | |
| Full time caregiver | 1 | 28 |
| Unemployed | | 1 |
| Unskilled | | 5 |
| Skilled in trade/profession | | 1[a] |
| Part time | 1 | |
| Full time | 1 | |
| Student | | 9[a] |
| Part time | | |
| Full time | | |
| Marital Status[b] | | |
| Married | 3 | 17 |
| Common law | | 11 |
| Separated | | 5 |
| Divorced | | 1 |
| Single | | 11 |
| Gross Family Income[c] | | |
| Under $10,000 | | 12 |
| $11,000-$20,000 | 3 | 23 |
| $21,000-$30,000 | | 6 |
| Over $31,000 | | 2 |

[a]part time or full time status not specified [b]n=45 [c]n=44 [d]n=43

Characteristics for primary caregivers (See Table 2). In this study, all three of the self-identified primary caregivers were women, and each identified themselves as biological mothers to the children in their care. The ages of the primary caregivers fell into each of the following age ranges: 26-30 years, 31-35 years, and 36-40 years, with the range of ages being 29 to 36 years. The cultural backgrounds of the primary caregivers were varied (one each of Spanish, German/Irish, and Lebanese), and two spoke English as a second language moderately well (i.e., did not need a translator). All three had less than high school education, with only one having completed some senior high. One primary caregiver identified herself as a full time caregiver, while the other two indicated they were also working outside the home. All three primary caregivers identifed themselves as married. With respect to total family income before taxes, all three primary caregivers reported incomes that did not exceed $20, 000 per year which is well below the low income cut off for families in Alberta, and for Canada as a whole (Edmonton Social Planning Council, 1997). Data from the two samples were difficult to compare given the sample size differences.

Characteristics of Children (See Table 3). The three children who were the focus of this study were all female; and of the three, two are now seven, and one is nine years old. At the time of the original study, all children were pre-schoolers (i.e., ages three to five years). In the original study there were 20 male children, and 36 female children, ages unidentified. Each child had an identified need: one had a medically identified diagnosis (Attention Deficit Disorder); one had an identifed need in the area of speech articulation, while one had an identified need in the area of language and communication. In the original study, there were 31 without an identified diagnosis; six with allergies/asthma; two with epilepsy/seizures; two with Attention Deficit Disorder; and three with 'other'. In this study, siblings in the family fell into three age groups: one in the zero to five year range, and three in the six to twelve year range. Data from the original study on sibling age was unavailable. Only one of the children, age seven years, was identifed as still participating

in Headstart, and none of the children were participating in any other special/educational programs.

Table 3

Children's gender, diagnosis, need, number of siblings per family, participation in Headstart or other programs

| Characteristic | Frequency | |
|---|---|---|
| | This study, n=3 | Original Study |
| Gender | | |
| Male | | 20 |
| Female | 3 | 36 |
| Age | | data unavailable |
| 5-7 | 2 | |
| 8-10 | 1 | |
| Diagnosis | | |
| None identified | 2 | 31 |
| Allergies/Asthma | | 6 |
| Epilepsy/Seizures | | 2 |
| Attention Deficit Disorder | 1 | 2 |
| Other | | 3 |
| Need | | |
| None identified | 1 | 13 |
| Speech/Articulation | 1 | 10 |
| Language/Communication | 1 | 2 |
| Behaviour | | 10 |

(table continues)

| Characteristic | | This study, n=3 | Original Study |
|---|---|---|---|
| Number Siblings/Family | | | |
| None | | | 4[a] |
| One | | 2 | 20[a] |
| Two | | 1 | 14[a] |
| Three | | | 4[a] |
| Four | | | 1[a] |
| Five | | | 2[a] |
| Number of Siblings/Family by Age Grouping | | | |
| 0-5 years | One | 1 | data unavailable |
| | Two | | |
| | Three | | |
| 6-12 years | One | 1 | |
| | Two | 2 | |
| | Three | | |
| Child still attending Headstart | | | |
| Yes | | 1[c] | |
| No | | 2 | |
| Child participation in special/educational program other than Headstart | | | |
| Yes | | | |
| No | | 3 | |

[a]n=56 [b]n=43 [c]n=39 [d]n=45 [e]Currently attending with sibling.

Characteristics of Interventionists (See Table 4). The three interventionists who responded were all female. They reported varied educational backgrounds related to their profession. Two of the interventionists have a background in early childhood

with one having a masters degree specializing in special education. The other interventionist has a masters degree in speech pathology. Together, the interventionists' practical experiences with families include: working as a kindergarten teacher, consulting with families of children who have autistic characteristics, working as a grade one teacher and pre-school director; leading a toddler play group, working with multi-disabled children, and currently as a speech pathologist in private practice.

Table 4

Interventionist's gender, education, profession, current job/position.

| Characteristics | Frequency |
|---|---|
| Gender | |
| Female | 3 |
| Male | |
| Education | |
| High School diploma | |
| Trade School or Technical Institute | |
| Some College/University | |
| College Diploma | 1 |
| University | |
| Bacclaureate | |
| Masters | 2 |
| Doctorate | |
| Post-Doctorate | |
| Profession/Occupation | |
| Teacher/Early Interventionist/ | 1 |
| Parent Support Facilitator | |
| Early childhood/Pre-school teacher | 1 |
| Speech-Language pathologist | 1 |

(table continues)

| Characteristic | Frequency |
|---|---|
| Current Job/Position | |
| Gr. 1 Teacher | 1 |
| Pre-school Director | 1 |
| Speech pathologist (private practice) | 1 |

Note. n=3.

Characteristics of Researchers (See Table 5). The three researchers each have a minimum of doctorate education, and have varying undergraduate and graduate education and experience. The researchers' education backgrounds include child health nursing, clinical child psychology, and educational psychology. As well, the researchers' practice experience with families varies. One operates an independent practice in family centered approaches, consulting to early intervention programs to aid in building capacities in child rearing families. One has had experience teaching in early education programs, as a child development consultant for Services for the Handicapped, psychologist and coordinator of the Communication Behaviour Program at Glenrose Hospital--working with families of children and adults with disabilities and children at risk. The third researcher has spent 35 years working with families in various capacities and roles. All three researchers have worked with families in both research and practice settings.

Table 5

Researcher's gender, education, profession, and current job/position

| Characteristics | Frequency |
|---|---|
| Gender | |
| Female | 2 |
| Male | 1 |
| Education | |
| Diploma | |
| University | |
| Baccalaureate | |
| Masters | |
| Doctorate | 2 |
| Post-Doctorate | 1 |
| Profession | |
| Nursing | 1 |
| Clinical Child Psychology | 1 |
| Teacher/Educational Psychology | 1 |
| Current Job/Position | |
| Professor (nursing), clinical research leader at Perinatal Research Centre | 1 |
| Professor Emeritus, Clinical Director Autism Linkages Program | 1 |
| Professor (Education), and Associate Chair Department of Educational Psychology, Associate Dean Faculty of Graduate Studies and Research | 1 |

Note. n=3

How was family centered practice implemented?

The investigator utilized several methods in order to measure how FCP was implemented in the original study: comparative analysis of the interventionist manuals to the principles of FCP (i.e., there were three manuals: an introduction to FCP, and a manual specific to each of the interventions); the independent variable (i.e., the intervention) schedule is compared to both the principles of FCP and to the interventionists' notes; and, a summary analysis was carried out with the interventionists' notes to identify family centered items. The five FCP principles are: 1) an effort to fully involve families in active decision making regarding their, and their child's care; 2) development of services for the entire family, not just the child; 3) involvement of families in program planning and service delivery; 4) the family's choices regarding their level of participation is respected; and 5) recognizes the parents as experts with regards to their family's needs and priorities. In the analysis principles one and three were difficult to identify separately.

Table 6

Presentation of Manuals: Instances of FCP principles per Manual.

| Principle | Introduction | NTS | CFL | Total |
|---|---|---|---|---|
| 1 | 41 | 75 | 69 | 185 |
| 2 | 45 | 17 | 12 | 74 |
| 3 | 41 | 75 | 69 | 185 |
| 4 | 20 | 11 | 4 | 35 |
| 5 | 43 | 21 | 6 | 70 |
| Total | 190 | 199 | 160 | ** |

Table 6 shows the presence and frequency of each principle by manual. All five principles are evidenced throughout the three manuals. Some principles are more prevalent than others. In some cases, broad general statements in the manuals made repetition unnecessary. In general, the NTS manual had a higher incidence of each principle than the CFL manual.

After identifying the items according to the five FCP principles, the researcher determined that there were items that did not fit the five principles used in this study, yet were considered 'family centered' as they fit with some of the nine principles outlined by the ACCH (1995). Also, the five principles used in this study overlapped with the nine identified by the ACCH. All nine of the ACCH's principles were also evidenced through out the three manuals.

The independent variable schedule was also compared to the five FCP principles, and strategies utilized by the research team to incorporate the family centred principles into the schedule were identified. As table 7 illustrates, all five principles are evidenced in the schedule for each NTS and CFL.

Table 7

Strategies that Illustrate FCP Principles per Intervention Schedule

| | Strategies | |
|---|---|---|
| Principle | NTS | CFL |
| 1 | -assessment/intervention, etc. takes place in family's home. (also fits with principles 3 & 4); explaining purpose of study again, and how often the interventionist would be visiting as part of the study; and what would be covering in that time; reviewing contracts so there is complete understanding of each interventionist/family responsibilities; explaining what will be done 'next time'; arrange scheduling of appointments to suit family needs; check re: meeting time still OK; leave time for questions from family. | -assessment/intervention, etc. takes place in family's home. (also fits with principles 3 & 4); explaining purpose of study again, and how often the interventionist would be visiting as part of the study; and what would be covered in that time; ask family for a situation they would like to address using WE CAN; contract with the family which 'Agree' skill they want to focus on. |
| 2 | -family focused assessment; allowing time to get to know the family, not just the child; interest in developing rapport with family; working with the family at each visit; families become active participants by doing family homework (i.e., together); focus on | -family focused assessment; allowing time to get to know the family, not just the child; interest in developing rapport with the family; working with the family at each visit; families become active participants by |

(table continues)

| | | |
|---|---|---|
| | family accomplishments. | doing family homework (i.e., together); ask family for a situation they would like to address using WE CAN; contract with the family which 'Agree' skill they want to focus on. |
| 3 | -as for above two principles. | -as for above two principles. |
| 4 | -family members are asked if there is continuing consent at each visit; families are able to ask the questions they want at each visit (more or less interaction); families are able to withdraw at any time (given instructions on how to do so). | -family members are asked if there is continuing consent at each visit; families are able to withdraw at any time (given instructions on how to do so). |
| 5 | -family input on needs/priorities; effort to ensure opportunity to answer questions the family may have; families given a phone number to contact the interventionist in case they have questions, or want to withdraw from the study; manual is left with the family for them to work through; asking for parents' opinions on their child's problem behaviour. | -family input on needs/priorities; family chooses which family situation they would like to address using WE CAN; family chooses which Agree skill they want to focus on. |

The investigator reviewed the interventionists' notes (notes made by the interventionists after each home visit) in order to compare them to the independent variable schedule and found that the notes were non-substantive and contained mainly notes regarding the process written for the interventionists themselves (e.g., 'met at arranged time' and 'nobody home'). These notes were also used to compile a summary of family centered items, and what occurred during the home visits for each family interviewed. It was then presented during the interview to confirm what the interventionists had written. The following are the summaries for each family.

Family 1: had a different interventionist for each intervention; mother and children present at visits; dad working out of town; first intervention is NTS; consent was confirmed; interventionist was flexible around meeting times, and changed times for visits because of family needs; did homework and work sheets (if not done, did it with the family, or found other ways of doing the same thing); respected mother's choices in doing homework and 'exercises'; provided an overview for the family of what was to be covered, and reviewed what had been covered during past visits; showed concern for particular family situations; acknowledged the good things mother was doing and progress being made; was flexible in meeting mother's needs (who said she was a better speaker than reader/writer of English), and assured the mother that she was easily understood; showed respect for mother's/family's needs during visits (i.e., showed signs of being tired, sick, when visitors arrived, religious holidays, etc.); gave examples and asked mom for her own examples; showed an interest in the family's activities separate from the interventions, i.e., asked to be shown Arabic games to show her own children; checking where they were at with the skills, etc.; interventionist available while family practices to help, encourage, re-inforce; first interventionist introduced next interventionist and went over the post intervention questionnaire with mom; went briefly through what the next 12 weeks would be like; thanked mom for letting her in; and offered opportunities for mom to ask any questions throughout.

Family 2: had NTS only; often it was only the mother home; interventionist went over the manual with the mother in stages to let her know what was coming up; reviewed what had already been covered; interventionist went through homework and work sheets with the mother; interventionist was encouraging and acknowledged the good things the mother was doing; interventionist was flexible in meeting the family's needs and helped fill in homework/work sheets; interventionist was flexible regarding meeting times and activities; interventionist respected the families' choices regarding their level of participation; interventionist offered explanations; interventionist was available while family practices to help, encourage, reinforce, etc.; interventionist gave examples and asked the mother for her own examples; checked where family at and how things were going; offered opportunities to ask questions throughout; interventionists thanked the mother for her time, effort, and for letting the interventionist into her home.

Family 3: had CFL first, had a different interventionist for each intervention; mother only present at visits; interventionist went over material to be covered, and reviewed past material; went through the homework/worksheets with the parent at each visit; interventionist showed concern regarding your family's situation; interventionist was flexible and helped with homework/work sheets, meeting times, and went over some things on the phone; interventionist acknowledged the good work mom was doing--like working out situations; interventionist checked how things were going/where at with the skills, working things out, etc.; explained ahead of time what would happen--like when the family switched interventions and interventionists. For NTS: the interventionist checked regarding the family's need for child care; again, flexible regarding meeting times, etc.; interventionist provided ample review time and overview time; interventionist offered encouragement to have dad present for the visits; interventionist offered opportunity for questions throughout; interventionist was very positive and encouraging regarding the mother's efforts; interventionist asked mother for feedback; thanked the mother for her time and involvement,

and for letting the interventionist into her home; and told the mother how much her work and effort were valued.

How was Family Centered Practice Experienced by Families

To determine how FCP was experienced by families in the original study the investigator reviewed the post-intervention surveys that the families completed for each intervention. The items in these surveys used a five point Likert type scale from 1=strongly disagree to 5=strongly agree. In addition, the families were interviewed. The goal was to verify and add to the data regarding the families' experiences gathered from the surveys that they filled out immediately after each intervention.

The results of the surveys for the families who were interviewed are compared to those of all the families who completed them in the original study, and are depicted in Table 8.

Table 8

Means and Ranges for Study Groups' Responses to Post-intervention survey; 1=strongly disagree, 5=strongly agree

| | NTS | | | |
|---|---|---|---|---|
| Question | Original Mean | Range | This Study's Mean | Range |
| I found the intervention helpful for my family | 4.0909 | 2 | 4.3333 | 4 |
| My interventionist was easy to work with | 4.9091 | 1 | 5.0000 | 0 |
| My interventionist treated me and my family with respect | 5.0000 | 0 | 5.0000 | 0 |
| Scheduling appointments was not a problem for me | 4.3636 | 3 | 4.3333 | 2 |
| I would not recommend this intervention to other families | 1.7273 | 2 | 1.3333 | 1 |
| I feel that getting involved with my child's play is important for both of us | 4.8182 | 1 | 4.6666 | 1 |
| I think I listen to my child more since doing the NTS intervention | 4.0909 | 2 | 4.3333 | 1 |
| The NTS manual was not helpful | 1.9091 | 2 | 1.3333 | 1 |
| The examples in the NTS manual fit really well with my experiences | 3.7273 | 3 | 4.0000 | 0 |

(table continues)

| Question | Original Mean | Range | This Study's Mean | Range |
|---|---|---|---|---|
| I need more time to work on problem behaviours. | 3.5455 | 3 | 3.3333 | 3 |
| It was really easy to find everyday things we already did and turn them into teaching opportunities | 3.9091 | 2 | 4.3333 | 1 |
| I try to take turns in play conversations with my child | 4.0000 | 0 | 4.0000 | 0 |
| I am the only person in the family who tries the things in the NTS intervention | 3.2727 | 3 | 4.6666 | 3 |
| I spend more time playing with my child | 3.5455 | 2 | 4.3333 | 1 |
| It is really hard to get the level right in a conversation with my child | 3.0909 | 3 | 3.0000 | 3 |
| The intervention really helped with some key issues | 4.0909 | 1 | 4.0000 | 0 |

| Question | Original Mean | Range | This Study's Mean | Range |
|---|---|---|---|---|
| We don't have as much fun when we play now. I'm always trying to teach something | 2.4545 | 4 | 3.3333 | 3 |
| There is too much homework in the intervention. | 2.0909 | 3 | 2.0000 | 2 |
| I would have liked to work longer on the NTS | 3.4545 | 3 | 4.0000 | 0 |
| Trying to talk about what was going on made things worse in my family | 1.7273 | 2 | 1.0000 | 0 |

CFL

| Question | Original Mean | Range | This Study's Mean | Range |
|---|---|---|---|---|
| I found the interventionist helpful for my family | 4.2500 | 2 | 5.0000 | 2 |
| My interventionist was easy to work with | 4.7500 | 1 | 5.0000 | 0 |
| My interventionist treated me and my family with respect | 4.7500 | 1 | 5.0000 | 0 |
| Scheduling appointments was not a problem for me | 4.4167 | 3 | 4.5000 | 1 |

(table continues)

| | | | | |
|---|---|---|---|---|
| We are now more positive about difficult situations | 4.2500 | 2 | 4.0000 | 2 |
| Question | Original Mean | Range | This Study's Mean | Range |
| I would not recommend this intervention to other families | 1.1667 | 1 | 1.0000 | 0 |
| I find it helpful to be able to look at situations using WE CAN. | 4.2500 | 2 | 5.0000 | 0 |
| I find it hard to describe what is going on | 2.3333 | 3 | 1.5000 | 1 |
| It is good to consider all options when you are faced with a difficult situation | 4.5833 | 1 | 5.0000 | 0 |
| I feel that as a family we talk more about what is going on since we had the intervention | 4.0000 | 2 | 4.0000 | 0 |
| It is important to listen to everyone's point of view | 4.7500 | 1 | 4.5000 | 1 |
| It is not possible to be assertive without being aggressive | 2.1667 | 2 | 2.5000 | 1 |
| I intend to keep using the WE CAN strategies | 4.0833 | 2 | 4.0000 | 0 |
| I was the only one in the family who really used WE CAN | 3.1667 | 3 | 4.0000 | 0 |

| | | | | |
|---|---|---|---|---|
| I would recommend the WE CAN intervention to a friend | 4.0833 | 2 | 4.5000 | 1 |
| I think the WE CAN helped me to have a better understanding of what is going on in my family | 4.4167 | 2 | 5.00000 | 1 |
| The WE CAN has not made a difference to how my family works together | 2.3333 | 3 | 3.0000 | 2 |
| The examples in the WE CAN handouts were realistic and helpful for me | 4.0000 | 4 | 3.5000 | 1 |
| There was too much homework in this intervention | 2.5833 | 3 | 1.0000 | 0 |
| I would have liked to work longer on the WE CAN with my interventionist | 3.5000 | 3 | 3.0000 | 2 |
| Trying to talk about what was going on made things worse in my family | 1.5833 | 2 | 2.0000 | 2 |
| Using WE CAN has made us feel more successful as a family | 3.9167 | 3 | 4.5000 | 1 |

Note: There were data missing for the original study results. For NTS there were 48 missing, and for CFL there were 47. For original study: NTS n=11 and CFL n= 12. For this study: NTS n=3 and CFL n=2 (i.e., one family had only received NTS).

The families who were interviewed reported positive experiences with the interventions and interventionists, which concurred with data from their surveys, and with data from the original study. It should be noted that all three families (i.e., mothers) reported elapsed time as a factor affecting their recall. The families also reported that they were in agreement with the strategies identified to incorporate the family centered principles into the schedule, the manuals, and the interventions. The family interviews were analyzed according to pre-established categories, with an openness to others that may have emerged. No new categories were identified. These categories were: satisfaction, sustainability, FCP principles, facilitating factors and barriers to FCP.

With regards to satisfaction, the families reported being very satisfied with the interventions and the interventionists, but many could not give specific examples. All families reported they would recommend each of the interventions to a friend; would not change either of the interventions; and when presented with the satisfaction survey for each intervention they completed immediately post-intervention, they stated that their comments remained the same regarding their satisfaction level.

Although the families spoke favourably of the interventions, they were unable, for the most part, to recall the specifics of the interventions, even when prompted with outlines and key words by the researcher. Although the families stated that the interventions helped them, they were generally unable to identify specifically how this was so. However, two families did identify one specific aspect of an intervention that helped them (one after being prompted with the outline/key words, the other without prompting). For example, "...from...the whole program, I got little bits of everything, like breaking down the situation, and how to change it to make it work better...It was all satisfying for me because then I could pick out of everything that applied to our family from each area...The...most

helpful things...getting down to their (the child's) level." Another family, after prompting, commented that taking turns was one of the things that stuck with them. Interestingly, turn taking and breaking down the situation are foundational skills in NTS and CFL respectively. All families stated that the interventions did not worsen their family situation.

Sustainability was addressed by asking questions about the past and present use of skills from the interventions. Generally, the families had difficulty recalling the interventions, and could not identify specific skills used then or now. With some prompting, most families remembered key words and recognized the intervention outlines. Only one family reported currently using (..."on a daily basis"...) a skill learned from one of the interventions. Families reported the following reasons why they used the skills less and less over time: no time; too busy (work inside and outside the home); moms were the only parent involved; wanted to 'just play' and not be concerned with always teaching something; no ongoing contact with the project to keep motivation up; 'didn't work, so didn't use them'. All families reported that they didn't notice any difference in family interactions. One family reported that they had dropped all but two of the skills because "I took what worked for my family". Interestingly, all families reported that they had difficulty identifying where they learned the skills they did have, and that they suspected they used some of the skills unconsciously without being able to identify them. One mother reported that the skills were refreshed as her younger child was reaching the age and stage the older child had been when they participated in the project.

With regards to the five FCP principles, the families all agreed with the summaries of the interventionists' notes that identified strategies used to incorporate the FCP principles into the interventions. When presented with each of the five principles of FCP, the families were unanimous that the interventions met these criteria.

Facilitating factors for FCP were identified by the families as being interventionists who were well trained and well suited to working with families. Barriers to FCP were identified by the families as being: spouses welcome, but not participating out of choice or

circumstance; mothers doing the bulk of the work at home (and for some, working outside the home as well), as well as the 'work' related to participating in the project, lead to mothers discontinuing what tasks they could, and that meant not practicing the skills for the interventions to decrease their workload.

How do the Families', Interventionists', and Researchers' Reported Experiences of FCP inform understanding of FCP?

In order to answer the question, "how do the families', interventionists', and researchers' reported experience of FCP inform understanding of FCP?", the investigator utilized information gathered from the independent variable schedule, the intervention manuals, the interventionists' notes, and the post-intervention surveys the families completed as discussed above. In addition, information was gathered from family interviews, and questionnaires administered by e-mail to the interventionists and the researchers (with the exception of one researcher who preferred to be interviewed). Presented here is what the three participant groups reported regarding their experiences. This question will be further addressed in the discussion section of this thesis.

As discussed above, the families reported that they were in agreement with the interventionists' view of what occured during the home visits, and that they were generally very satisfied with the interventions both at the time, and at the later interview approximately three years later. Although the families interviewed were pleased with the interventions, none of them had consciously sustained the interventions in their entirety. The families all agreed that the five FCP principles were illustrated in both interventions. Through content analysis, facilitating factors and barriers to FCP were identified.

The interventionists and researchers all agreed with the summary of what happened during the study, including what took place during the home visits while acknowledging that elapsed time was a factor in their recall. One researcher added that the interventions were piloted prior to being implemented in the study. The interventionists reported that prior to participating in the original research project, two were familiar with FCP, while the

other had heard of FCP, but was not overly familiar with it. All three researchers reported being familiar with FCP prior to the study. At the time of this study, none of the interventionists were involved in the ongoing original research, although one works in the private sector with families and NTS, and is taking course work related to NTS and CFL. Another interventionist reported incorporating some of the knowledge and skills into her private practice. The researchers all reported experiences with FCP in varying capacities since the completion of the project. The interventionists reported their ideas of FCP as: "...putting the family in control of the services they receive and the manner in which those services are delivered. It respects and accomodates to the individual needs, strengths, and preferences of each family"; and, to "...work collaboratively with a family as a team....Together an assement is done...and mutually agreed upon goals (are set)...based on the needs...of the family....The interventionist should plan her work around what the family wants and needs rather than a preset agenda or program the interventionist wants to implement." These statements encompass and reflect the commonly accepted defintions of FCP. However, a recurring theme in the interventionists' responses is that the interventions were as family centered as they could be, given the confines of the 'scientific' nature of the research. This meant that families were given as much control as possible, and interventionists were as flexible as they could be, but that certain things (i.e., the intervention schedule) were necessarily prescribed. The researchers provided similar definitions that specified families as being a key element in all levels of practice and at every stage of involvement with families; and which encompass the five FCP principles.

Of the two interventions, CFL was seen by the interventionists to be more family centered because of its flexibility in addressing whatever issue the families choose to address. NTS was seen as necessarily more rigid because of the prescribed skills taught in a sequential order that build upon each other. The interventionists found it challenging to be truly family centered while following the research protocol, and felt that outside the research setting, families would be provided with more of a "...'smorgasbord' of services

and information... allowing them to...mix and match whatever suits their strengths and needs at the time." They also commented that it was up to the interventionists to implement the approaches in a family centered way. The researchers agreed with the interventionists, and stressed that the interventions are not, and in fact were not meant to be, family centered when looked at in isolation. They too stressed the need to implement the interventions using the FCP principles. One researcher verbalized the concept of partnership with families as an "attitude...needed to effectively implement the approaches".

The interventionists' and researchers' responses were analyzed according to pre-established categories, as were the family interviews. The results of this analysis follow. Commenting on the satisfaction they felt the families experienced, the interventionists said that on the whole, families were very satisfied with the interventions at the time; and, although there were a few families who felt the whole process was a 'waste of time', most families got more out of one intervention than another depending on their needs. NTS was seen as being enjoyed more by the children, and CFL was seen as being enjoyed more by the parents. Interventionists felt that in some cases, different examples would be beneficial (i.e., more age appropriate in NTS, and alternate situations to Billy's Boots in CFL) for parents, and may make a difference in how parents respond to the interventions. They also felt that by taking part in the original study, the families were re-affirmed in the positive things they were doing and the skills they already had, and that "...parents appreciated being treated as equal partners and felt good about being listened to without being judged". The researchers agreed with the interventionists' comments, and reported that they too had the impression that the families thought the interventions and skills learned were useful and could be applied to a variety of situations.

The interventionists reported that more than once, families mentioned that they "...wished they had learned the...skills when they had started parenting rather than four years later." One interventionist reported that she thought it would be ideal to start working with these families prenatally, or when the children were babies and continue through the

pre-school years. The researchers concurred that introducing the skills as early as possible would be ideal. These comments concur with the current early intervention, education and psychology research regarding the powerful influence early experiences (i.e., prenatally to age six) and environment have on a child's brain development, thus affecting the overall development of that child.

With regards to sustainability, the interventionists felt that even with much practice in their presence, a lot of families did not reach fluency with the skills in each intervention, and that the manuals "...would not even be opened after..." (the research was completed). In regards to the CFL, the interventionists stated that they couldn't ...see the parents going through all the steps on their own...after finishing the intervention". Reasons given for this are: not being on board, being in severe crisis, and time constraints on practice and review. The interventionists were not surprised to hear that the families recall of the interventions was weak because of the lack of fluency reached at the time of the study, and the time elapsed since their participation. "If you don't use it, you lose it", was identified by the interventionists as the main reason why families were not currently fluent; and that perhaps the skills were not learned when they were the most useful or relevant for the families. The fact that families took what they needed from the interventions was seen as being positive, in that a small impact was better than no impact at all. Also mentioned was the idea that perhaps the skills were being used unconsciously, especially with families who already possessed certain skills. Possible reasons given for why NTS was more recognizable to families than CFL were: "...it is easier to talk to a stranger about NTS as it centers around your children rather than your own personal family situations..."; "Perhaps the skills in NTS are easier as they are quite natural, the CFL skills are a little more technical, wordy, and private"; and that the technical language in CFL may be hard for some to remember. The researchers concurred with the interventionists and also noted that 'fluency' was an issue related to time and context, and that they too felt that perhaps parents

were using at least some of the skills from the interventions unconsciously (i.e., "...not recognizing that the skills have become part of the way they deal with difficult situations").

When asked about the five FCP principles, the interventionists reported that generally all five were incorporated in implementing the interventions. However, even though family choice was incorporated as much as possible, a recurring theme that emerged is that families were not as fully involved as they could have been if outside of a research setting. The researchers agreed with the interventionists and stressed again the fact that the interventions are not family centered on their own, and that it is how they are implemented that makes them family centered.

The main facilitating factor to FCP identified by the interventionists was good listening skills in order to identify, and then discuss with the family, their needs and possible options to meeting those needs. Interventionists also suggested skills related to assisting the family to choose an appropriate option, and providing support to follow through with it, as a facilitating factor to FCP. The researchers added other faciliating factors to FCP: learning the skills using context appropriate and meaningful examples and situations chosen by the families; introducing the skills to parents as early as possible; parents supporting each other; and good communication between interventionists and families. Barriers to FCP were identified by the interventionists as: families being in crisis; lack of time to reach fluency; a rigid protocol related to the research agenda; and that most often, only one parent of a two parent family participated in the interventions. In addition, the researchers identifed barriers to FCP as being: cultural differences in the roles of children and parents; and in the value of play; motivation of parents; and lack of immediate feedback on how parental/child relationships were changing for the better; lack of attention paid to 'entry skills' that would be helpful in developing the skills associated with the interventions; videotaped examples of the steps in each manual were not as effective as they could have been (i.e., child in the video was higher functioning than most children in the original study), which sometimes left families on their own to figure out the skills.

## Summary of Results

The primary caregivers who were interviewed represented a variety of age ranges, and occupations, but similar educational status's and incomes thus resulting in a good representation of the larger population of interest in this study. All were women and the biological mothers of the children in their care, were married, and had other children living in the household. Two of the mothers spoke English as a second language. None of the three mothers had completed high school, and all families reported gross family income as being $20,000 per year or less. Two were employed outside the home, while one was a full time care giver.

The children of the families interviewed were essentially 'normal', healthy children who had had some developmental delay, and were in grade school at the time of the interview (pre-schoolers at the time of the original study). The children of concern in the original study had all taken part in Headstart as pre-schoolers, but only one was still attending. None of the children were currently enrolled in any other educational programs. It also appears that the children in this study are essentially equivalent to the sample in the original study.

The interventionists possessed varied educational and professional backgrounds and were knowledgeable regarding FCP. Based on their experiences implementing the interventions and working with families, they offered some suggestions for future development and implementation of the interventions, as well as some insights into why things happened the way they did. The researchers also came from varied educational and professional backgrounds, and were understandably knowledgeable regarding FCP. Based on their experiences developing the interventions, and learning what the families and interventionists had to say about the interventions, they offered further insight into the process and outcome of the original research as well as the current study.

Families reported being satisfied with the interventions and the interventionists and researchers reported this was their impression as well. All participants felt the five FCP

principles were met to some extent, acknowledging the research agenda put some limitation on the family centeredness of the interventions. Facilitating factors and barriers to FCP were identifed by the three groups, and the issue of sustainability was addressed by the interventionists and researchers. Of note is the concept that the interventions are not family centered when looked at in isolation, and that how they are implemented is the key to their meeting the criteria for FCP.

# Chapter 5

## Discussion

In chapter 5 the discussion of the research findings in relation to the literature is presented. Three practice elements necessary to implement FCP emerged: 1) attitudes and skills the interventionists have and use to implement FCP; 2) support to the interventionists from programs and agencies; and, 3) appropriate practices that focus on building family capacities. There were two main findings in this project related to these three elements that have become issues of interest. The first has to do with the notion that the skill building aspects of the interventions are separate from, but related to, FCP. The second idea that recurred throughout the data is that of fluency. These issues are presented and followed by discussion of implications for nursing practice, nursing education, the interventions, and FCP. Finally, limitations, strengths, and directions for future research are outlined.

### Skill Building in Families Versus Family Centered Practice

The intent of the researchers in the original study was to develop family centered interventions that would focus on the families' strengths, and would enhance resiliency and therefore adaptation. The focus of this study was to evaluate the family centeredness of the NTS and CFL interventions. That is, for this study, the process of implementation of FCP was more important than resiliency outcomes.

### FCP Principles

According to the families, interventionists and researchers, the five essential elements common to many descriptions of FCP, and used in this study for evaluation purposes, were met. The overall impression was that: the interventions were developed for the entire family, not just the child; families were involved in program planning and service delivery; the family's choices regarding level of participation were respected; and, parents were recognized as experts with regards to their family's needs. Although an effort was made to fully involve families in active decision making regarding the family's, and the

child's care, and the families responded that this was so; the professionals reported that FCP was not instituted as fully as possible because of the research agenda.

A major finding of this study is the emergence of the concept that FCP encompasses more than focusing on families, or capacity and skill building in families. There are certain skills required of interventionists, and support from the programs they work within, that are essential. A discussion of these ideas follow.

The Client Focus of FCP

The families interviewed, and in fact all families from the original study, fit the profile of those typically targeted by FCP: families of children with special needs, and families at risk for health and social problems (CICH, 1994; ESPC, 1997; Health Canada, 1997). In this case, the 'special need' refers to a developmental delay identified in the pre-school child. Risk factors for health and social problems are as follows: low parental education, low income, substance/physical abuse, and single parenthood. The families in this study, as in the original study, had at least two of these risks. As suggested in the literature, these risk factors often co-occurred which puts these families at even greater risk as the effects may be multiplicative rather than simply additive.

Staff Attitude, Knowledge and Skill

Common sense tells us that in order to effectively implement family centered programs or interventions, one must have qualified staff who are sensitive to the needs of families with special needs who are at risk for health and social problems. The health care provider must believe that people are competent or have the capacity to be competent. This condition was met in the original study as evidenced by the comments made by the interventionists and the researchers. Both the interventionists and researchers stated that they felt, and indeed the families supported this, that the families were recognized as the experts with regards to their families' needs and priorities. They also indicated this belief in their responses to the question regarding what FCP means to them. "Family centered practice means to work collaboratively with a family, as a team. Together goals are set,

based on the needs and goals of the particular family. The interventionist should plan her work around what the family wants and needs rather than a preset agenda...". "Family centered practice...involves putting the family in control of the services they receive and the manner in which those services are delivered." These statements imply a belief in, and respect of, the family's competency, or capacity to be competent.

Identified in the literature was the need for families to be viewed as more than 'consultants' in their health care. FCP empowers families when they have access to, and control over the necessary resources; take control of and responsibility for, decision making and problem solving; and acquire the means to do so (Dunst, Trivette, & Deal, 1988). Again, families, interventionists, and researchers in this study reported that families were recognized as the experts regarding their family's needs; and were given as much control and flexibility within the interventions as possible, given the confines of scientific research. Families were supported in their natural caregiving roles by building on strengths they already possessed. Outside of the controlled research setting, families would be given a range of options, and not be limited to the two interventions of the original study.

Support from Employing Programs and Agencies

The ACCH (Shelton & Stepanek, 1994) recognizes staff support as one of its nine essential elements of FCP. In the original study, the interventionists were chosen for their personalities combined with their educational and practice backgrounds. They were provided with training regarding FCP and the interventions, and had access to the researchers who developed the interventions and were knowledgeable regarding FCP. This is in accordance with findings that a lack of education and knowledge regarding FCP among staff acts as a barrier to implementing FCP (Letourneau, 1994). The interventionists were also supported in the process of implementing FCP when they participated in debriefing sessions with the researchers where they identified problem areas and discussed situations as they arose.

The interventionists' introductory manual specifies that two of the assumptions necessary to implementing the interventions are: that staff "already have expertise in the areas of child development, adaptive program planning, and knowledge of the availability of community resources and strategies to access these resources; and, that "most families are functioning well within a healthy range of family adaptation, and that the role of the interventionist is to support and nurture the goals and activities of the family members within this context of positive family adaptation" (Alexander, Kysela, McDonald, & Drummond, 1996, p. 2). Staff, as a key element in the process of implementing FCP, emerged from all participants' data.

The researchers stated that the interventionists had undergone an intensive one month training period on the interventions and on FCP itself. They also acknowledged the ability of the interventionists to implement the interventions in a family centered manner, and the fact that the interventionists were initially chosen for their abilities, personalities, and overall fit with a family centered approach. The introduction manual also outlines the philosophy, guidelines and procedures necessary to implement the interventions. The first page of the manual outlines the assumptions underlying the interventions. The main one with regard to the family's role is that "family members are competent, interested in providing the best possible education for their children and are experts when it comes to identifying their own strengths, needs, skills, and goals for their children" (Alexander, Kysela, McDonald, & Drummond, 1996, p. 2).

In summary, the adaptive abilities of at risk families are continually taxed, as they encounter tremendous stress, both intense and chronic. FCP, as a comprehensive approach to child and family health that focuses on strengths and protective mechanisms of families, was essentially present in the delivery of the interventions in the original project. NTS and CFL were targeted at families in order to enhance their abilities to adapt successfully when facing the challenges of life and child-rearing. Even given all of these facts, the findings indicate an uneven uptake of the skills in both the NTS and CFL. Is it

the skill building approaches, the FCPs, or a combination that bears on fluency? Two approaches to the issue of fluency are present in the literature. In learning theory, fluency is essential at each phase of learning. In family empowerment, fluency is an element of the control necessary for management of family situations.

## Fluency

### Fluency and the Learning Process

Learning is a complex activity that is difficult to describe or define, and is commonly thought to be a more or less permanent change in behaviour that occurs as a result of activity or experience, noting that not all changes in behaviour result from learning (e.g. weight gain, sleeping, influence of drugs, etc.). Learning includes not only the "acquisition of knowledge and skills, but also of attitudes and values" (Verner & Davison, 1971, p.1). It is generally agreed that there are three phases of learning: acquisition, maintenance, and generalizability or transfer (Slavin, 1997). These phases are sequential, and the element of fluency, increases as the learner moves through them.

In the acquisition phase, learners practice skills with an interventionist who is able to prompt, model, and reinforce the skill. Learners practice until they get it right with the interventionist. Learning the skills in this phase requires intensive and spaced practice, repetition, and positive reinforcement. Maintenance is the second phase of learning and is the "continuation of behaviour" (Slavin, 1997, p. 168). That is, the learner practices on his or her own with exercises initiated from outside him/herself. Providing cues, or signals as to what behaviour(s) will be reinforced, is an important stimuli that precedes a behaviour and influences maintenance of skills (Slavin, 1997). Generalization, or transfer, of skills is the "carryover of behaviours, skills, or concepts from one setting or task to another" (Slavin, 1997, p. 170), and occurs when the learner can recall, and use correctly, the skills as needed. Also associated with generalization, is the ability for the learner to verbally identify the 'why' or 'how' of the skill.

Acquisition, maintenance and generalization of the NTS and CFL skills were the goals of the original project. In order to assist families in achieving acquisition, the interventions incorporated some repetition and intensive, spaced practice during the bi-weekly visits. The literature indicates that spaced practice is more effective than massed practice; and that spaced practice is of particular importance during the early stages of learning where error is more apt to occur. Massed practice at this time may lead to a performance error that is learned so well, it is difficult to unlearn and correct (Verner & Davison, 1971). The researchers indicated that meetings, and therefore practice, with families were too spaced and perhaps could have been weekly to promote acquisition of skills. The indication from families, however, is that this may be too much of a commitment for them. Although the interventionists provided positive reinforcement, the data supported the idea that the amount they provided was less than ideal. This is partially due to the research agenda, and that more time was required for practice in order for acquisition of skills to occur; and the fact that sufficient practice was not built into the interventions.

Homework was the main way intended for families to work on maintenance of skills. However, as the participants reported, homework was often done with the families. Although very family centered, this researcher argues that, in fact, interventionists and families doing homework together meant that the majority of families did not move beyond acquisition. Further development of cues and prompts were suggested by the interventionists and researchers to assist families in maintenance of skills.

Reported in the literature is the idea that, unlike in the early stages of learning where positive reinforcement should be frequent and predictable; once behaviours are established, reinforcement should become less frequent and less predictable. The reason for this is that "variable schedules of reinforcement and (those) that require many behaviours before reinforcement is given are much more resistant to extinction than are fixed schedules or easy ones" (Slavin, 1997, p. 168) (i.e., extinction being the weakening, and ultimately the

disappearance of skills). Had most of the families achieved acquisition, the amount and timing (i.e.,variable ratio and variable interval) of reinforcement during maintenance may have been adequate.

Preparation for generalization of skills in the original project was addressed through the use of repetition, positive feedback, homework, layering skills (i.e., learning skills in a logical sequence) and learning the skills in the setting (i.e., the home) where they will ultimately be used. Data from the participants indicates, that again, even more time for repetition, practice and meta-communication (i.e., modeling and allowing the family to talk about the changes they were seeing related to the skills they were learning) is required. The suggestion of increased time raises another issue. Although increased time is recognized by the interventionists and researchers as being a facilitating factor in learning skills; the families reported that more time spent (i.e., at least as a research participant) may not be desirable or feasible for them.

Also of note with regards to fluency and learning the skills, is the finding that families reported currently using only 'turn taking' and 'breaking down the situation'. These skills form the basis upon which other skills build in the NTS and CFL respectively, and as such were introduced early on in the process, repeated, and practiced relentlessly.

Fluency: A Condition Supportive of Family Empowerment

The three conditions outlined in the literature for the family centered goal of family empowerment to exist (Dunst, Trivette, & Deal, 1994) are discussed as they relate to the original study. 1) The healthcare giver must believe that people are competent or have the capacity to be competent; 2) opportunities must be created for competence to be learned or displayed; and, 3) family members must be able to attribute their behaviour change to their own actions in order to acquire the sense of control necessary to manage family affairs.

The condition that the health care provider must believe that people are competent or have the capacity to be competent is an attitude that was fully discussed earlier in this

chapter. The findings indicate that this condition was reached in the original research project.

The second condition that opportunities must be created for competence to be learned or displayed was also discussed previously in this chapter. It was found that although families felt ample opportunities were provided, the interventionists and researchers recognized the need for more time for practice and repetition, which is necessary in all aspects of the learning process. 'Turn taking' and 'breaking down the situation', the foundational skills of the NTS and CFL respectively, were those recalled and utilized by families almost three years after the end of the original project. This implies that opportunities for competency to be learned or displayed occurred for these two skills, but were insufficient for the subsequent skills.

In addition, this researcher notes that the training interventionists receive to use prompting and cueing needs to be further developed, as do the prompts and cues themselves; and more prompted opportunities also need to be provided. Another barrier to the second condition is a lack of opportunity to apply skills to different situations within the interventions. Homework provided families with additional opportunities to think about and practice skills, either on their own or with the interventionist. More positive reinforcement is seen as creating an opportunity for learning, in that it models a desirable behaviour while motivating the learner.

The interventions fell somewhat short of the third condition that family members must be able to attribute their behaviour change to their own actions in order to acquire the sense of control necessary to manage family affairs. Acquisition of skills was uneven, which implies that maintenance was insufficient, and generalization was not always the outcome. Reasons for this cited by the interventionists and researchers, and put forward by this researcher, include: lack of immediate positive feedback, and that this type of feedback occurred sporadically throughout the interventions but was not consistent when needed; a schedule of providing feedback was not directly included in the interventions; the

research protocol was such that time was not unlimited, and time was allowed for the required steps only and not much outside of them; and opportunities for the interventionists to talk with the families, and for families to talk, about what they were doing, and changes that were occurring were minimal also for the reasons cited above.

Both the interventionists and the researchers suggested that, other than the obvious time factor, and providing for more practice and scheduled positive feedback within the interventions, one way to meet this third condition is through the use of video feedback. Video taping interactions and playing them back to the families while pointing out, and having families point out, what they are doing and the effects their actions had on their children and the whole family, would assist the family in attributing their behaviour change to their own actions.

Barriers to the third condition for family empowerment are also those that influence families achieving fluency in the intervention skills. Of interest is the fact that again, the skills that the families recalled and reported currently using, were 'turn taking' and 'breaking down the situation'. As the basic skills of the NTS and CFL respectively, they were talked about repetitively (i.e., the notion of meta-communication) thus allowing for families to eventually attribute the changes they were seeing with the skills they were using and to recall and apply the skills beyond the homework and practice situations.

In summary, fluency is an important factor in both skill building and in empowering families, the goal of FCP. Practices identified in this study that promote capacity building are: meta-communication; prompting; cueing; modeling; repetition; continuous reinforcement that gradually changes to a variable schedule; intensive, spaced practice; practice skills with the interventionists and on own; sufficient quantity and quality of prompts and cues; contextually appropriate learning; opportunities for capacities to be learned or displayed; opportunities for families to attribute their behaviour change to their own actions; and, interventions are planned and learned over an appropriate period of time.

Practices/skills identified that promote FCP are: a belief that families are competent, or have the capacity to become competent; a belief that families are the experts with regards to their needs and priorities; opportunities for competence to be learned or displayed; opportunities for families to attribute their behaviour change to their own actions; meta-communication; choosing and training interventionists to fit with the philosophy of FCP; interventionists that are sensitive to needs of at risk families of children with special needs; and, interventionists who are able to work as members of an interdisciplinary team that includes the families.

Finally, identified supports to FCP are: debriefing of interventionists; interventionists having access to experts on FCP; training interventionists in FCP and related interventions and skills; access to practices that promote family capacities; an environment supportive of interdisciplinary teamwork; and, an environment supportive of FCP in theory and practice.

## Implications

There are a number of implications for nursing that arise from the findings of this study. First, the implications for nursing practice will be considered. This is followed by discussion of implications for nursing education, and for the interventions and FCP. Finally, limitations, strengths and directions for future research will be addressed.

### Nursing Practice

In today's health care system, nurses' roles are constantly changing and expanding, as is the definition of health. The conceptual shift from professional to family as expert, and individual to family context, and the subsequent changes in professional nursing practice are of theoretical and practical importance. As nurses become more adept at assessing and working with families, they must find approaches to working with families that provide the best possible outcomes. FCP is an approach that allows nurses and other health care professionals to assist families in caring for themselves. The family is viewed

as the focus of intervention, and strengths and protective mechanisms are stressed so that families build skills that will serve them now and in the future.

This conceptual shift may be new for many professionals and family members who are accustomed to the 'professional as expert' paradigm. A new relationship needs to be forged between families and professionals that recognizes, values and supports "the partnership in ways that are culturally appropriate and consistent with the role parents desire" (Bailey, Hebbeler, Simeonsson, Spiker, and Wagner, 1998, p. 314). For FCP, nurses need to develop, implement, and evaluate programs using the FCP principles and the skills required of effective family centered practitioners: listening, discussing, meta-communication, prompting, cueing, modeling, practicing and positive reinforcement. In this way, programs meet the criteria for FCP, while also meeting the learning and empowerment needs of families.

A common role for nurses is that of referral agent. Nurses must be aware of the available community supports, and the most effective and efficient methods of linking families to them. Also related to this point is the importance of nurses being team members, and being able to work collaboratively with families and other professionals.

Anything nurses can do within their scope of practice to reduce the impact on families of having a special needs child, and having other risk factors proven to be detrimental to their health, and to that of their children, needs to be done. Early life experiences are critical in the development and overall health of children. Focusing on the family is one way nurses can influence the health of families and their children. And the earlier the intervention, the better. While never too late to stimulate a child's health and development, the groundwork needs to be laid as early as possible. Nurses must be aware of the benefits of FCP at all levels of intervention.

Nursing Education

If nurses are going to effectively implement FCP, they need to be educated in the philosophy of FCP, and in the practices and skills inherent in a FCP approach. Nursing

curricula ought to reflect this need. Undergraduate and graduate level courses in FCP, either in nursing or multidisciplinary faculties, are one way to provide the expertise needed to effectively implement FCP. Another is offering specialty nurse practitioner programs in the area of FCP. Also of extreme importance, is the education of interventionists, who may or may not be nurses. As noted earlier, the interventionists are key in FCP, as it is often how an intervention is implemented that determines its family centeredness. Key areas of education for anyone implementing a FCP approach are knowledge, skills, and attitudes.

Knowledge. Knowledge about the needs of families, types of families, child development, FCP (i.e., philosophy, assessment, interventions, and evaluation), and associated practices are important aspects of any education program. Specifically, service providers need to be knowledgeable regarding:

-the needs of families of special needs children, particularly those with various other risk factors;

-assessment of health needs of children and their families;

-family dynamics;

-knowledge, mobilization and enhancement of community resources;

-learning theory;

-FCP;

-discrete and transferable practices;

-goals of meta-communication;

-basic communication skills; and

-positive reinforcement.

Family centered practitioners need to be aware of the difference between capacity building and FCP. Accordingly, facilitating factors and barriers to these are also areas in which family centered practitioners need to be knowledeable. Practitioners also need to be knowledgeable at the level of program design to develop programs that execute FCPs

which would ideally, in turn, enhance capacity building in families. In order to effectively implement FCP, service providers need to be prepared in the above areas to best meet the needs of families and make the most of their strengths.

Skills. Nurses and other service providers who work from a FCP perspective need to have excellent communication, assessment, and intervention practice skills. These are key in assisting families to identify needs, goals, possible plans of action, and in providing necessary feedback to them. Meta-communication and positive reinforcement are essential in the learning process and in family empowerment; as is the ability to plan for, and effectively implement and evaluate, the phases learning. Being sensitive to the particular needs of families of special needs children, and families at risk, is imperative. Interdisciplinary team work and case management are other important skills for all FCP practitioners, as often families will identify needs that require a variety of services.

Attitudes. An attitude that respects families, and recognizes parents as experts with regard to their family's needs and strengths is key, and needs to be fostered in all service providers involved in FCP. Service providers also need to be aware of their own attitudes regarding different family types and situations so that they are less likely to influence their practice. The five FCP principles utilized in this study, and the nine outlined by the ACCH (Shelton & Stepanek, 1994), are essential for family centered practitioners to maintain. Practitioners adhering to a FCP philosophy would focus on family needs and strengths, protective mechanisms, adaptive abilities, and empowering families. A belief that families are capable and competent must underlie all interactions with them.

The Interventions: NTS and CFL

Implications for the interventions relate back to the issue of fluency and the factors that were identified as influencing the learning of the skills. The findings indicate that programs such as the one evaluated for this thesis should be spread over longer periods of time. This would allow families to work at their own pace, and to incorporate more repetition, reinforcement of skills using various situations, and practice with the families.

The results also indicate the need for further development of prompts and cues within the NTS and CFL. More immediate feedback via video, or other methods, needs to be provided by the interventionists in order for families to notice changes in behaviour, and to attribute those changes to the skills they were learning and using. Families need the opportunity to talk about what they are doing, why they are doing it, and the changes they see. Of note are the suggestions by the interventionists to utilize these, and similar interventions, with parents prenatally, or when their children are babies. Another important suggestion is to do future research in the area of testing for unconscious use of intervention skills. Other changes to the interventions are beyond the scope of this thesis.

In summary, various approaches may not be family centered when looked at in isolation. The manner in which approaches are implemented is what makes them family centered. This implies that it is often the practitioner that is charged with following the FCP principles, and implementing FCP. It is clear that further work needs to be done in the area of developing family centered programs and approaches. Also, attention needs to be paid to the separation of skills possessed by the families that promote capacity building, from the skills possessed by interventionists, and the characteristics of programs, necessary to implement practices in a family centered manner . It is also evident that further research be done in the area of the kinds of supports from programs that enable practitioners to follow a family centered approach. Also, it is imperative that the gaps between research, practice, and education be eliminated for FCP to become the norm, and for effective application of the FCP principles.

## Limitations, Strengths, and Directions for Future Research

### Limitations

The primary limitation of this study was the inability to reach saturation of data. A greater response from the families would have provided richer data. Two of the three mothers who were interviewed were not very verbose, but the interviews had to be used because of the low number of respondents. Another limitation is that two of the three

families interviewed spoke English as a second language moderately well which raised the issue of comprehension. Although the investigator made every attempt to be clear, keep questions short, and clarify, she was not always sure the mothers understood. Elapsed time since the completion of the original study was acknowledged by all three groups of participants as a factor in their recall, yet long-term recall of the families was of interest in this study. Another limit of note is that the nature of the questions administered to the mothers provides an individual perspective on a family level situation. Circumstances led to only mothers being interviewed, when ideally both partners, and even older children, would be interviewed. This is acceptable in that all efforts were made to include partners, and that mothers are frequently the family's spokespeople regarding children and health matters.

Strengths

The researcher feels that the research standards of fit and competence of data collection and analysis; credibility; and value constraints, and the manner in which they were met, as discussed in chapter three are worth noting here, however they will not be revisited. The only addition to the discussion regarding research standards is that through this study, the researcher learned many things that will improve future research endeavours.

A major strength of this research was to provide the opportunity for at-risk families of children with special needs to voice their opinions regarding the interventions in which they had participated. This same opportunity was provided for the interventionists and researchers. The researchers also had the unique opportunity to reflect on the anonymous responses of both the families and the interventionists, and to take these responses into consideration when conducting further research, or for further developing the interventions. Interviews with the families allowed for a sense of trust to develop and to accommodate any minor language and reading skill barriers. Utilizing electronic mail to send questionnaires to the researchers and the interventionists allowed for an inexpensive,

and convenient, although not always expedient, method of distribution and collection of the data; particularly with the interventionist who had relocated overseas since the completion of the original project. Of particular importance, this study illustrates a number of issues that implementing FCP and associated practices raises, and provides direction for nursing practice, education, and nursing research.

Directions for Future Research

Because of the gap between research, practice, and education in the area of FCP and related approaches, there are a number of routes nursing research can take. More investigation into the process of implementing FCP is necessary. Current approaches need to be evaluated for their family centeredness, and new family centered interventions developed, tested and evaluated. The merits of evaluation research, and determining if so called family centered programs are truly family centered, needs to be expounded. Researchers need to focus on the three elements of FCP: FCP skills; practices that enhance capacity building in families; and supports to FCP. This includes incorporating the perspectives of families and other participants in the process.

Research in the area of effective family centered programs needs to be explored and further discussion around the outcomes of FCP needs to be generated. That is, do FCP programs achieve the outcomes expected, and what are those outcomes? Outcomes related to the effectiveness of a program in changing family behaviour are distinct from, but no less important than, outcomes related to enabling and empowering families. Research studies need to focus on both of these types of outcomes. Another area of research, is in studying the skills necessary to implement FCP, and the desirable characteristics of people that implement FCP. These research endeavors may lead to a model of FCP that could be substantiated and used to guide our thinking and our practice in working with at risk families of children with special needs.

Comments in Hindsight

In thinking through the analysis, the results, and the discussion, several thoughts occurred to the investigator. A discussion of these ideas follow. The first has to do with the notion of what the investigator would do over, given the opportunity.

-As alluded to previously, accessing more families to achieve rich, saturated data would be ideal.

-Re-administering the post-intervention satisfaction surveys would provide a better 'before and after' comparison of the families' perceptions on the interventions.

-Utilize one or more of the tools (i.e., MPOC or FAMprs) to evaluate family centered practices, and to enhance the analysis of the interventions.

-E-mail questionnaires to interventionists and researchers was not as useful or as expedient as anticipated. Respondents probably felt overwhelmed, especially if unfamiliar with e-mail or were poor typists, when trying to respond in one session, instead of answering a question or two at a time. Also, there was no exchange between members of the same group, as the investigator had hoped. This may have provided the stimulus necessary to start a discussion, instead of a question and answer format. There are arguments for respondents being either more, or less, responsive via e-mail. Another thing considered in hindsight was that some respondents might read the whole document before replying to the questions, and that thay may have influenced how they responded. In this case, focus groups may have been a more viable option for accessing these participants views.

-An evaluative study, such as this one, would be better started right after completion of the original project. However, the investigator believes there is merit in the 'three years later' point of view, as it provides valuable information regarding utilization and recall of skills that were the focus of the interventions in the original project.

The second thought has to do with what influenced the responses, particularly from the families. The investigator was not entirely confident that the families did not participate

out of a sense of obligation, or concern for how it would appear if they were to decline. This issue is a concern for the investigator, especially in research that involves disadvantaged populations, and accesses participants through an agency or program.

The third thought follows from the second, and that is considering what effect the investigator had on the responses of the families in particular. Even though careful consideration was given to dress and demeanor, it was impossible to disguise the fact that the investigator was 'different' from the family respondents. The fact that the investigator was there doing 'research', first set them apart. Also, the interviews with the two families who spoke English as a second language did not go as well as they might have, even with clear, simple communication. In both instances, peer reviewers may have been helpful.

By no means are the issues discussed above the only ones related to this study. They are merely the ones that come to mind immediately. The investigator learned several lessons as a result of the research process, and will take them on to future endeavours in research and in working with families. It is hoped that perhaps future researchers might also learn from them as well.

## Conclusion

The results of this study indicate that there are three main elements to FCP: 1) the FCP skills; 2) support to the interventionists from programs and agencies; and 3) appropriate practices that focus on building family capacities. Although all three elements are equally important, and all three were touched on in this chapter, it is the first two on which the researcher focused. Discussion regarding further development of the interventions other than that presented here is beyond the scope of this thesis. The two main findings related to these elements were: 1) that skill building that focuses on the families' strengths and capacities are separate from, but related to FCP; and, 2) there was a recurring theme of fluency throughout the data.

The data gathered for this study supports the view that the NTS and CFL interventions are only family centered when implemented as such. The findings emphasize

the need for: practitioners to be skilled in the implementation of FCP and related practices; further development of approaches, and on going training and support of staff in those approaches, that focus on the family's strengths and protective mechanisms to facilitate the successful adaptation of all families over their lifespan. When implemented according to the five principles of FCP, these interventions aim at strengthening and building family resources, and can positively influence child development. In addition, staff development is unquestionably one of the foundations for effectively implementing FCP. The issue of fluency in the skills of the intervention is important and needs to be addressed in their further development. The findings of this study have implications for nursing practice, education, the refinement of the interventions, and FCP. Limitations and strengths of this study were acknowledged, and directions for future research outlined.

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## Appendices

Appendix A: Nine principles of Family Centered Practice

Appendix B: Five principles of Family Centered Practice used in this study

Appendix C: Letter of permission to access data from original study

Appendix D: Independent variable schedule from original study

Appendix E: Family satisfaction surveys from original research

Appendix F: Correspondence with participants

- Families
  - Information Letter
  - Consent
  - Interview Questions
  - Demographic questionnaire
  - Request for results
- Interventionists
  - Information letter
  - Demographic questionnaire
  - Questionnaire
- Researchers
  - Information letter
  - Demographic questionnaire
  - Questionnaire

Appendix G: Ethical approval

Appendix A

## Nine Principles of Family Centered Practice

(Shelton & Stepanek, 1995 & IWK Family Centered Care Committee, 1992)

1. The family as the constant. Recognizing that the family is the constant in a child's life, while the service and support systems fluctuate, and incorporating this into policy and practice. The two critical aspects of this key principle are: 'family' and the diverse definition of the word; and the the degree to which services are 'centered' around the family members who play a pivotal role in the life and care of the child.

2. Family/professional collaboration. Facilitating collaboration among professionals and families at all levels of hospital, home, and community care, from assessment through evaluation, as the means to achieving the vision of FCP. This element is a practical and respectful way to humanize the delivery of health and developmental services, and it improves the outcomes for children needing specialized care and support.

3. Exchanging complete and unbiased information between families and professionals in a supportive manner at all times. Effective communication which encompasses the unbiased and ongoing exchange of information, is essential to FCP as it ties all of the principles together. True collaboration demands that families and professionals work together to openly exhange information, ideas, and concerns.

4. The diversity of families. Incorporating into policy and practice the recognition and honoring of cultural diversity, strengths, and individuality within and across all families, including ethnic, racial, spiritual, social, economic, educational, and geographic diversity. The fundamental idea of FCP is that children are best served when they are understood as inextricably linked to a larger living unit, their families. FCP requires that each family be approached anew, with a recognition of, and respect for, their diversity.

5. Coping and support. Recognizing and respecting different methods of coping and implementing comprehensive policies and programs that provide demelopmental, educational, emotional, environmental, and financial supports to meet the diverse needs of

families. Although there are many issues that may be common to families whose children need specialized services, it is critical that professionals respect each family's individuality in their adaptation to their child's needs and to address the specific goals expressed by each family. Families are unique in the meanings they ascribe to an illness or disability, the impact is has on various family members and the family as a whole, and the way they choose to meet the new challenges they face.

6. Peer networking. In FCP, it is the role of the professional to encourage and facilitate family-to-family support and networking. It is important to recognize that previously established sources of support may not be adequate for families of children with special needs. As well as networking with these supports, it is important for many families to have contact with other families facing similar challenges.

7. Coordinated services and supports. Ensuring that hospital, home, and community service and support systems for children needing specialized health and developmental care and their families are flexible, accessible, and comprehensive in responding to diverse family-identified needs. This element is particularly important as the one thing that can be anticipated in the life of a child with a chronic illness or disability, is that the child and family will have a variety of needs that will require exposure to a multitude of services and professionals, and that their needs will change over time. Caregivers must be prepared to effectively deal with future concerns, needs, and aspirations. This element incorporates not only whether needs are met, but also the manner in which the mobilization of resources occurs, and whether or not resources contribute to the enablement and empowerment of families to collaborate fully as equal partners in their children's care.

8. Appreciating families as families and children as children. This element recognizes that families and children possess a wide array of strengths, concerns, emotions, and aspirations beyond their need for specialized health and developmental services and support. It is important for professionals to recognize, accept, and support the

fact that the child's health condition may not always be the family's only or most central priority, and that their needs will change over time.

9. Staff support. In order for the other principles to be implemented fully and effectively, professionals and other staff involved in FCP need to be supported through policies and programs that are comprehensive and provide emotional support to meet the needs of staff in their practice and education .

Appendix B

**Five Principles of Family Centered Practice:**

For evaluative purposes, the following FCP principle were utilized

1) An effort to fully involve families in active decision making regarding their, and their child's, care.

2) Development of services for the entire family, not just the child.

3) Involvement of families in program planning and service delivery.

4) The family's choices regarding their level of participation is respected.

5) Recognizes the parents as experts with regards to their family's needs and priorities.

Appendix C

**Letter of Permission to Access Data from Original Study**

University of Alberta
Edmonton
Canada T6G 2G5

**Centre for Research in Applied Measurement and Evaluation**
Faculty of Education
3-102 Education Centre North, Telephone (403) 492-3762
Fax: (403) 492-3179

Date: February 18th 1998

To: Panel B: Health ethics revue Board

From: Gerard M. Kysela Ph.D.
Professor Emeritus, Education

Linda McDonald, Ph.D.
Professor, Education

Jane Drummond, Ph.D.
Professor, Nursing

Re: Access to subjects from, and Secondary Analysis of Data from the study "Enhancing resiliency through family interventions with children at risk for life long developmental disorders"

We are more than happy to provide access to subjects and to the data from the study "Enhancing resiliency through family interventions with children at risk for life long developmental disorders" to Kim Cook who is carrying out a study called "Operationalizing Family-Centred Practice".

Appendix D

**Independent Variable Schedule from Original Study**

## Week One

- introduce yourself to the family
- short visit just to get acquainted and do a general assessment on the family

- develop rapport with the family
- play with the child
- explain the purpose of the study again, how long you will be with the family (how often)

- explain what next twelve weeks will be covering:
  Natural Teaching Strategies
  Communication with Child

- review contract with family so there is a complete understanding of responsibilities

- explain what will be done next week
- re-cap time meet etc.
- exchange phone numbers in case cancel etc.
- answer any questions

**Leave Fridge magnets, parent manual and duotang**



## Week One

- introduce self to family (exchange phone numbers in case of cancel)
- insure there is continuing consent
- get acquainted and do a general assessment

- develop rapport with family
- play with child
- explain purpose of study,

- explain time commitment
  - will be with family one and half hours every other week

- OVERVIEW
- briefly explain what next twelve weeks will be covering
- utilize worksheet "WE CAN"
  - side one WE CAN
  - side two WE HAVE THE SKILL

- MAJOR CONCEPT
  - positive approach include the notion of cooperation
  - utilize worksheet "Situations are Good Things"

- HOMEWORK
  - ask family to spend some time thinking about their goals
  - leave worksheet "Alike and Different"

- RECAP
  - utilize worksheet "accomplishments, homework, next meeting"

- SUPPLIES
  - "WE CAN" (NEW)
  - "Situations are Good Things" (NEW)
  - "Alike and Different" (NEW)
  - "Recap" (NEW)
  - Binders for the family
  - Project card

## Week Two

Focus: Chapter One
"Child's Lead: Turn Taking"

Introduce:

- communication with child
- fun aspect
- conversations - balanced/imbalanced
- following the child's lead
- step by step guide to conversations
- turn taking



## Week Two

- insure there is continuing consent

- REVIEW - using homework or current situation
  review positive approach and goals the family set
- **reinforce doing homework**

| | |
|---|---|
| - MAJOR CONCEPT | - describe behavior<br>- utilize worksheet "So, what is the situation?" |
| - HOMEWORK | - practice describing behavior<br>- leave the worksheet "What is going on?" |
| - RECAP | - "accomplishments, homework, next meeting" |
| -SUPPLIES | - "Situations are Good Things"<br>- "Alike and Different"<br>- "So, what is the situation?" (NEW)<br>- "What is going on?" (NEW)<br>- "Recap" |

## Week Three

Focus: review Chapter One "Child's Lead: Turn Taking"

Review:
- communication
- conversations
- steps

Introduce:
- definitions
- "But what if..." (okay if things go wrong)
- summarize main points thus far

Homework:
- Turn Taking Through Imitation (chart)

**Take extra homework charts**

## Week Three

- insure there is continuing consent

| | |
|---|---|
| - REVIEW | - using homework or current situation review worksheet<br>"What is going on?"<br>- **reinforce doing homework** |
| - MAJOR CONCEPT | - brainstorming<br>- utilize worksheet "A storm of ideas" |
| - HOMEWORK | - practice describing behavior and brainstorming<br>- leave the worksheets "What is going on?" and "Evaluate the options" |
| - RECAP SHEET | - "accomplishments, homework, next meeting" |
| - SUPPLIES | - "What is going on?"<br>- "A storm of ideas" (NEW)<br>- "Evaluate the options" (NEW)<br>- "Recap" |

## Week Four

Focus: Chapter Two "Keeping Action Going"
Review:
- turn taking and communication
- imitating child's behavior
- homework/questions

Introduce:
- balancing turns

- reinforce "Natural" - i.e. doing these interactions at normal times in the day

- match your child's level of communication

## Week Four

- insure there is continuing consent

| | |
|---|---|
| - REVIEW | - using homework or a current situation review "What is going on?" and "Evaluate the options" |
| - **reinforce doing homework** | |
| - MAJOR CONCEPT | - search skills<br>- utilize worksheet "Resources" |
| - HOMEWORK | - Practice describing behavior, brainstorming and search skills<br>- leave worksheets "What is going on?", "Evaluate the options" and "Can anyone help?" |
| - RECAP | - accomplishments, homework, next meeting |
| - SUPPLIES | - "What is going on?"<br>- "Evaluate the options"<br>- "Resources" (NEW)<br>- "Can anyone help?" (NEW)<br>- "Recap" |

## Week Five

Focus: review concepts in Chapter Two "Keep Action Going"

REVIEW:
- balancing

- natural

- matching levels

INTRODUCE:
- steps -

**Wait**
**Signal**
**Prompt**

HOMEWORK:

- Your Turn (chart)

- Wait/Signal/Prompt (chart)



## Week Five

- insure there is continuing consent

- REVIEW - using homework or a current situation review worksheets "What is going on?", "Can anyone help? and "Evaluate the options"
- **reinforce doing homework**

- MAJOR CONCEPT - planning
  - utilize worksheet "Notice the difference" (sections A - C)

- HOMEWORK - practice describing behavior, brainstorming and search skills and feedback
  - leave worksheets "What is going on?", "Evaluate the options", "Can anyone help?" and "Notice the difference"
  - focus on feedback by using "Notice the Results" section D

- RECAP - accomplishments, homework, next meeting

- SUPPLIES
  - "What is going on?"
  - "Evaluate the options"
  - "Resources
  - "Can anyone help?"
  - "Notice the difference" (NEW)
  - "Recap"

## Week Six

Focus: Chapter Three "Expansion - Adding"

REVIEW:
- wait/signal/prompt
- turn taking

INTRODUCE:
- brainstorming things parents tried with children

- checklist
  - part everyday routine
  - turn taking
  - longer conversations
  - having fun
  - type feedback from children
  - trying strategies with other children
  - notice changes in child's behavior
  - notice changes in own behavior

- expansion - adding to the conversation, make it more interesting
  (3 steps)



## Week Six

- insure there is continuing consent
- REVIEW - using homework or a current situation review WE CAN skills
  - utilize worksheets "What is going on?", "Evaluate the options", "Can anyone help?" and "Notice the difference"
- **reinforce doing homework**
- MAJOR CONCEPT - Agree

ask for a family situation that the family would like to address using WE CAN.
contract with the family which Agree skill they want to focus on.

Rule: By the end of Week 11 each of the following agree skills must be a focus once.
- listening
- leading
- contributing
- confronting
- perspective taking and ownership
- assertiveness

- HOMEWORK
- practice WE CAN
- focus on the selected Agree skill
- leave worksheets "What is going on?", "Evaluate the options", "Can anyone help?", "Agree" and "Notice the difference"
- RECAP - accomplishments, homework, next meeting
- SUPPLIES
  - "What is going on?"
  - "Evaluate the options"
  - "Resources
  - "Can anyone help?"
  - "Notice the difference"
  - "Agree" and appropriate section from the parent manual (NEW)
  - "Recap"

## Week Seven

Focus: Review Chapter Three "Expansion-Adding"

REVIEW:
- expansion - adding to the conversation (3 steps)

INTRODUCE:
- getting child's attention

- solutions for ongoing problems (brainstorm)

- expectations (finding child's level)

HOMEWORK:
- Expansion (chart)



## Week Seven

- insure there is continuing consent
- REVIEW - using homework or a current situation review WE CAN skills
- utilize worksheets "What is going on?", "Evaluate the options", "Can anyone help?" and "Notice the difference"
- **reinforce doing homework**
- MAJOR CONCEPT - Agree

ask for a family situation that the family would like to address using WE CAN.
contract with the family which Agree skill they want to focus on.

Rule: By the end of Week 11 each of the following agree skills must be a focus once.

listening
leading
contributing
confronting
perspective taking and ownership
assertiveness

Cross out the skill dealt with in week 6
Circle the skill chosen for week 7
- HOMEWORK
- practice WE CAN
- focus on the selected Agree skill
- leave worksheets "What is going on?", "Evaluate the options", "Can anyone help?", "Agree" and "Notice the difference"
- RECAP - accomplishments, homework, next meeting
- SUPPLIES
  - "What is going on?"
  - "Evaluate the options"
  - "Resources
  - "Can anyone help?"
  - "Notice the difference"
  - "Agree" and appropriate section from the parent manual (NEW), "Recap"

## Week Eight

Focus: Chapter Four "Incidental Teaching"
Review:
- get child's attention
- solutions for problems
- expectations

Introduce:
- skills to further child independence
- incidental teaching (natural)
- modeling
    - imitation
    - good models
    - hints for imitation



## Week Eight

- insure there is continuing consent
- REVIEW - using homework or a current situation review WE CAN skills
- utilize worksheets "What is going on?", "Evaluate the options", "Can anyone help?" and "Notice the difference"
- **reinforce doing homework**
- MAJOR CONCEPT - Agree

ask for a family situation that the family would like to address using WE CAN.
contract with the family which Agree skill they want to focus on.

Rule: By the end of Week 11 each of the following agree skills must be a focus once.
- listening
- leading
- contributing
- confronting
- perspective taking and ownership
- assertiveness

Cross out the skill dealt with in week 6 and 7
Circle the skill chosen for week 8
- HOMEWORK
- practice WE CAN
- focus on the selected Agree skill
- leave worksheets "What is going on?", "Evaluate the options", "Can anyone help?", "Agree" and "Notice the difference"
- RECAP - accomplishments, homework, next meeting
- SUPPLIES
    - "What is going on?"
    - "Evaluate the options"
    - "Resources
    - "Can anyone help?"
    - "Notice the difference"
    - "Agree" and appropriate section from the parent manual (NEW), "Recap"

## Week Nine

Focus: review Chapter Four " Incidental Teaching"

REVIEW:
- incidental teaching

- modeling

INTRODUCE:
-prompting (3 steps)

- "Things To Remember"

HOMEWORK:
- Incidental Teaching (keeping track)

## Week Nine

- insure there is continuing consent
- REVIEW - using homework or a current situation review WE CAN skills
- utilize worksheets "What is going on?", "Evaluate the options", "Can anyone help?" and "Notice the difference"
- **reinforce doing homework**
- MAJOR CONCEPT - Agree

ask for a family situation that the family would like to address using WE CAN.
contract with the family which Agree skill they want to focus on.

Rule: By the end of Week 11 each of the following agree skills must be a focus once.
- listening
- leading
- contributing
- confronting
- perspective taking and ownership
- assertiveness

Cross out the skill dealt with in week 6, 7 and 8
Circle the skill chosen for week 9
- HOMEWORK
- practice WE CAN
- focus on the selected Agree skill
- leave worksheets "What is going on?", "Evaluate the options", "Can anyone help?", "Agree" and "Notice the difference"
- RECAP - accomplishments, homework, next meeting
- SUPPLIES
  - "What is going on?"
  - "Evaluate the options"
  - "Resources
  - "Can anyone help?"
  - "Notice the difference"
  - "Agree" and appropriate section from the parent manual (NEW), "Recap"

## Week Ten

Focus: Chapter Five "New Look Problem Behavior"

REVIEW:
- incidental teaching
- prompting

INTRODUCE:
- general talk about parenting and children misbehavior

- behaviors have meaning (interpretation)

- meaning behind behavior
  - attention
  - tangibles
  - self reward
  - escape

- interpreting the message - "message" worksheet

Discuss parent's examples of their child's challenging behaviors

## Week Ten

- insure there is continuing consent
- REVIEW - using homework or a current situation review WE CAN skills
- utilize worksheets "What is going on?", "Evaluate the options", "Can anyone help?" and "Notice the difference"
- **reinforce doing homework**
- MAJOR CONCEPT - Agree

ask for a family situation that the family would like to address using WE CAN.
contract with the family which Agree skill they want to focus on.

Rule: By the end of Week 11 each of the following agree skills must be a focus once.
- listening
- leading
- contributing
- confronting
- perspective taking and ownership
- assertiveness

Cross out the skill dealt with in week 6, 7, 8, and 9
Circle the skill chosen for week 10
- HOMEWORK
- practice WE CAN
- focus on the selected Agree skill
- leave worksheets "What is going on?", "Evaluate the options", "Can anyone help?", "Agree" and "Notice the difference"
- RECAP - accomplishments, homework, next meeting
- SUPPLIES
  - "What is going on?"
  - "Evaluate the options"
  - "Resources
  - "Can anyone help?"
  - "Notice the difference"
  - "Agree" and appropriate section from the parent manual (NEW), "Recap"

## Week Eleven

Focus: review Chapter Five "New Look Problem Behavior"

REVIEW:
- meaning in behavior
- interpreting

INTRODUCE:
- behavior that not directly communicating anything - "self-reinforcing"

- find the meaning (3 steps)

- finding an alternative behavior and reinforcing it

HOMEWORK:
- managing behavior

## Week Eleven

- insure there is continuing consent
- REVIEW - using homework or a current situation review WE CAN skills
- utilize worksheets "What is going on?", "Evaluate the options", "Can anyone help?" and "Notice the difference"
- **reinforce doing homework**
- MAJOR CONCEPT - Agree

ask for a family situation that the family would like to address using WE CAN.
contract with the family which Agree skill they want to focus on.

Rule: By the end of Week 11 each of the following agree skills must be a focus once.

listening
leading
contributing
confronting
perspective taking and ownership
assertiveness

Cross out the skill dealt with in week 6, 7, , 9 and 10
Circle the skill chosen for week 11
- HOMEWORK
- practice WE CAN
- focus on the selected Agree skill
- leave worksheets "What is going on?", "Evaluate the options", "Can anyone help?", "Agree" and "Notice the difference"
- RECAP - accomplishments, homework, next meeting
- SUPPLIES
  - "What is going on?"
  - "Evaluate the options"
  - "Resources
  - "Can anyone help?"
  - "Notice the difference"
  - "Agree" and appropriate section from the parent manual (NEW), "Recap"

## Week Twelve

FINAL THOUGHTS
Review:
- homework
- each Chapter briefly
- trouble areas
- answer questions

Focus On Accomplishments

Conclude:
- thank the family

- inform of the next responsibilities in the study

- schedule any necessary appointments etc.



## Week Twelve

- insure there is continuing consent

| | |
|---|---|
| - REVIEW | - utilize handout "WE CAN"<br>- side one WE CAN<br>- side two WE HAVE THE SKILL |
| - MAJOR CONCEPT | - focus on accomplishments<br>- organize the discussion around the WE CAN process and the WE HAVE THE SKILL skills |
| - HOMEWORK | - leave laminated WE CAN Sheets with an overhead pen |
| - SUPPLIES | - "What is going on?"<br>- "Evaluate the options"<br>- "Resources<br>- "Can anyone help?"<br>- "Notice the difference"<br>- "Agree" and appropriate section from the parent manual<br>- "Recap" |

-thank the family

- inform of next responsibilities in the study

- schedule any necessary appointments etc.

Appendix E

**Family Satisfaction Surveys**

Satisfaction Surveys from original study

Dear Parents:

Thank you for taking the time to complete this questionnaire.

We hope to keep track of how you have found the intervention so far. If you could answer these questions thinking back over the last six months and about how much you use the techniques you have learned it would help us a lot. This way we know if we are on the right track or whether we should be doing things differently.

**Please rate the following statements on a scale of 1 to 5.**

**1 = strongly disagree**
**2 = disagree**
**3 = neither agree nor disagree**
**4 = agree**
**5 = strongly agree**

1. I found the intervention helpful for my family.
   **1 2 3 4 5**
2. My interventionist was easy to work with.
   **1 2 3 4 5**
3. My intervenionist treated me and my family with respect.
   **1 2 3 4 5**
4. Scheduling appoitments was not a problem for me.
   **1 2 3 4 5**
5. We are now more positive about difficult situations.
   **1 2 3 4 5**
6. I would not recommend this intervention to other families.
   **1 2 3 4 5**
7. I find it helpful to be able to look at situations using WE CAN.
   **1 2 3 4 5**
8. I find it hard to be able to descrobe "What is going on?".
   **1 2 3 4 5**
9. It is good to consider all your options when you are faced with a difficult situation.
   **1 2 3 4 5**
10. I feel that as a family we talk more about what is going on since we had the intervention.

1 2 3 4 5

11. It is important to listen to everyone's point of view.

1 2 3 4 5

12. It is not possible to be assertive without being aggressive.

1 2 3 4 5

13. I intend to keep using the WE CAN strategies.

1 2 3 4 5

14. I was the only one in the family who really used the WE CAN.

1 2 3 4 5

15. I would recommend the WE CAN intervention to a friend.

1 2 3 4 5

16. I think the WE CAN helped me to have a better understanding of what is going on in my family.

1 2 3 4 5

17. The WE CAN has not made a difference to how my family works together.

1 2 3 4 5

18. The examples in the WE CAN handouts were realistic and helpful for me.

1 2 3 4 5

19. There was too much homework in this intervention.

1 2 3 4 5

20. I would have liked to work longer on the WE CAN with my interventionist.

1 2 3 4 5

21. Using WE CAN has made us feel more successful as a family

1 2 3 4 5

**What three things did you find most helpful from the WE CAN?**

1.

2.

3.

Dear Parents:

Thank you for taking the time to complete this questionnaire.
We hope to keep track of how you have found the intervention so far. If you could answer these questions thinking back over the last six months and about how much you use the techniques you have learned it would help us a lot. This way we know if we are on the right track or whether we should be doing things differently.

**Please rate the following statements on a scale of 1 to 5. 1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree.**

1. I found the intervention helpful for my family.
1 2 3 4 5

2. My interventionist was easy to work with.
1 2 3 4 5

3. My interventionist treated me and my family with respect.
1 2 3 4 5

4. Scheduling appointments was not a problem for me.
1 2 3 4 5

5. I would not recommend this intervention to other families.
1 2 3 4 5

6. I feel that getting involved with my child's play is important for both of us.
1 2 3 4 5

7. I think I listen to my child more since doing the NTS intervention.
1 2 3 4 5

8. The NTS manual was not helpful.
1 2 3 4 5

9. The examples in the NTS manual fit really well with my experiences.
1 2 3 4 5

10. I needed more time to work on problem behaviors.
1 2 3 4 5

11. It was really easy to find everyday things we already did and turn them into teaching opportunities.
1 2 3 4 5

12. I try to take turns in play and conversation with my child now.
1 2 3 4 5

13. I am the only person in the family who tries the things in the NTS intervention.
1 2 3 4 5

14. I spend more time playing with my child now.
1 2 3 4 5

15. It is really hard to get the level right in a conversation with my child.
1 2 3 4 5

16. The intervention really helped me with some key issues.
1 2 3 4 5

17. We don't have as much fun when we play now. I'm always trying to teach something.
1 2 3 4 5

18. There was too much homework in this intervention.
1 2 3 4 5

19. I would have liked to work longer on the NTS with my interventionist.
1 2 3 4 5

20. Trying to talk about what was going on made things worse in my family.
1 2 3 4 5

What three things did you find most helpful from the NTS?

1.

2.

3.

It would be helpful if, in the space below, or on the back of this page, you could add anything else that would help us in our evaluation of the intervention so far. Thank you!

Appendix F

**Correspondence with Participants**

Families:

1918 1998

FACULTY OF NURSING

University of Alberta
3rd Floor Clinical Sciences Building
Edmonton Alberta T6G 2G3
Canada

*Celebrating 80 Years of Excellence*

**Project Title: Operationalizing Family Centered Practice: Utilization of Data from an Intervention Study**

Researcher: Kim Cook, MN (C)
Faculty of Nursing, 3rd Floor, Clinical Sciences Building
University of Alberta
Ph. (780) ***-**** or 492-6685
E-mail: **********

Co-Investigator: Jane Drummond, Associate Professor
Faculty of Nursing, 3rd Floor, Clinical Sciences Building
University of Alberta
Ph. (403) 492-6410
E-mail: **********

**About the Researcher**

- my name is Kim Cook and I am a nurse
- I have permission to do this study as part of my masters thesis from the Faculty of Nursing at the University of Alberta **and**
- the Health Research Ethics Administration Board

**Reason for the Study**

- the home visiting study that you were a part of in 1995-1997 used two approaches
  - -Natural Teaching Strategies
  - -Cooperative Family Learning
- I am interested in giving families a chance to comment on these approaches
  - -were they useful?
  - -do you still use them?
  - -how involved did your family feel when the approaches were used with you?
- To improve the approaches used in the home visiting study

**Benefits of study**

- There are no direct benefits or risks to taking part in this study.
- Taking part in this study will not affect the services you receive now or in the future.
- The approaches used in the home visiting study will be improved.

**What will happen if you consent**

I will make one visit to your family:

- During this visit I will
  - -go over the study again and ask for your written consent
  - -ask certain things about your family so that I can describe you (income, education, marital status, number of children, etc.)
  - -I will summarize the approaches used in the home visiting study
  - -We will talk about how useful they are to you

-You will be able to say how suited **you** thought the approaches were for your family's situation
-You will be given a chance to comment on and add to, my summary of your survey and of what happened
-You will be able to ask that information not be included in the final report (this can be done at any time)

- a summary of **all** the interviews from families in this study will be given to the interventionists and researchers from the home visiting study
- they will discuss changes to be made to the approaches

**Tape Recording**

- I would like to tape record the interviews
- taping the interviews will make it easier for me to remember exactly what you said

**Please initial here if you do **NOT WANT TO BE TAPED** (I would like to take detailed notes during the interview)_____

**Security**

- **The researchers and interventionists will not know who you are.**
- Only I will be able to look at the interventionist's notes and surveys for your family
- Tapes of the interviews will be kept locked with other confidential material.
- A code will be used instead of your name on any of the information you give me, research reports or presentations.
- Your code and real name will be kept locked up separately from other information.
- Data from this study will be kept for seven years.
- Data from this study may be used in another study in the future if the researcher gets ethical approval.

**Communication**

- Taking part in this study is voluntary and confidential.
- You do not have to answer any questions you don't want to
- You can withdraw from the study at any time
- I will ask you if you still consent at each visit
- If you have any questions about this study, please call me **or**,
- You can call Dr. Janice Lander, Associate Dean, Research (phone: 492-6317) in the Faculty of Nursing if you have any questions or concerns about this study. This person is not part of the study.
- Results from this study can be gotten from myself by returning the Request for Results card given to you at the interview.

Thank you for taking the time to think about my study.

Sincerely,

**Initials:** Parent_____
Researcher_____

_____ _____
Kim Cook, BScN, MN (C) Jane Drummond, RN, PhD

FACULTY OF NURSING
University of Alberta
3rd Floor Clinical Sciences Building
Edmonton Alberta T6G 2G3
Canada

Consent

*Celebrating 80 Years of Excellence*

**Part 1:**
Title of Project: **Operationalizing Family Centered Practice: Utilization of Data from an Intervention Study.**

Principal Investigator: Kim Cook, MN (C), University of Alberta, Faculty of Nursing
Ph.: (780)-***-****
E-mail: **********

Co-Investigator: Jane Drummond, RN, PhD, Associate Professor, University of Alberta
Faculty of Nursing
Ph.: (780) 492-6410
E-mail: **********

**Part 2:** (Please circle one)

| | |
|---|---|
| Do you understand that you have been asked to be in a research study? | Yes No |
| Have you read and received a copy of the attached Information Letter? | Yes No |
| Do you understand the benefits and risks involved in taking part in this research study? | Yes No |
| Have you had an opportunity to ask questions and discuss this study? | Yes No |
| Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect the care or services you receive (or your professional position). | Yes No |
| Has the issue of confidentiality been explained to you? Do you understand who will have access to the information you provide? | Yes No |

This study was explained to me by: Kim Cook, MN (C), and
I agree to take part in this study.

_____ _____
Signature of Research Participant Date

_____
Printed Name

**********

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____ _____
Signature of Investigator Date

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT

Family Interview:

1. **Generally**, have things changed for your family since you participated in the home visiting study (i.e., a move, a change in job, a new baby, divorce, etc.)? If so, how?

2) Can you tell me briefly what you remember about the approaches (i.e., NTS & CFL)? (Review interventions from manuals if necessary).

3. (Present brief **summary analysis of the interventionist's notes** for their family visits) This is a summary of what the interventionist says happened during the study; is this how it happened for you? Can you give me specific examples of how it was the same or different for you?

4. SATISFACTION:

-Looking back on the interventions, how satisfied were you with each of the approaches: Natural Teaching Strategies? Co-operative Family Learning? Can you explain and give me examples of what you liked and didn't like?

-What changes would you like to see in the interventions?

-Now that you've had some time to try out the skills from the interventions, would (or have) you recommend either or both of the interventions to a friend?

(Present with a very general verbal summary of their own **surveys**)

-What changes would you make if you were to fill this form out again? If there are changes since you filled out these surveys, what are the reasons for them?

5. Can you give me specific examples of how the interventions have helped your family. Made things worse?

6. SUSTAINABILITY: Can you give me specific examples of how you **have used** what you learned from:

NTS? CFL?

-Can you give me specific examples of how you are **currently** using what you learned from the:

NTS? CFL?

-If you are not currently using information from the interventions, can you give me specific examples or reasons why this is so?

7. (Present with a verbal summary of each of the five **principles of FCP**, one at a time) I am using 4 criteria to evaluate both the NTS & the CFL....How do **you** think the interventions from the original study fits with this criteria? (NTS? CFL?)

8. What suggestions do you have for further developing the program to make it better for families such as yourself?

9. Do you have anything else you want to say about the interventions?

Demographic questionnaire for families

**Code No._____**

This data is being asked of you in case any information has changed since you took part in the original Natural Teaching Strategies/Cooperative Family Learning study, and to help me organize data I collect.

1. How many children are in your care (i.e., biological & otherwise)?

2. What is **your** relationship to the children in your care? What is their age, sex, diagnosis, and need? Please state for all children. (For **diagnosis** please state one of the following: None identified; Allergies/Asthma; Epilepsy/seizures; Attention Defecit Disorder; or Other-please specify). For **need** please state one of the following: None identified; Speech/articulation; Language/communication; Behaviour; or Other-please specify).

| Child | Age (in years) | Sex (M or F) | Diagnosis | Need | Relationship |
|---|---|---|---|---|---|
| 1 | | | | | |
| 2 | | | | | |
| 3 | | | | | |
| 4 | | | | | |

3. What are the ages and sex of all the people who are caregivers to the child(ren) (including yourself/ves)?

| Caregiver | Age |
|---|---|
| 1. | |
| 2. | |
| 3. | |

4. Does a child(ren) still take part in the Headstart program? If so, which child (by number, from question 2).

If not, when was the last time your child(ren) went to Headstart?

5. Has your child(ren) taken part in any other educational or special programs (other than Headstart) since you participated in the original study?

6. Please check the highest level of education that you have completed:

-Less than grade 7_____

-Junior High_____

-Some Senior High_____

-High School_____

-Some College_____

-College/University_____

-Technical Institute/Diploma_____

8. What is your occupation? (Check all that apply)

-Full time caregiver to the child/ren_____

-Un-employed_____

-Un-skilled_____

-Skilled in a trade or profession_____

Work Part-time_____

Work Full-time_____

-Student

-Part time_____

-Full time_____

9. What is your marital status?

-Married_____

-Common law_____

-Separated_____

-Divorced_____

-Single_____

10. What is your gross family income (i.e., before taxes)?

-Under $10,000_____

-$11,000-$20,000_____

-$21,000-$30,000_____

-Above $31,000_____

11. How would you describe your cultural background? (Eg. Metis, French-Canadian, German, and so on)

What is the cultural background of the other caregivers?

***Thank you for taking the time to answer these questions***

## Request for results

If you wish to receive a copy of the results from this research (**Operationalizing family centered practice**), please return this form in the self-addressed, stamped envelope. If the envelope gets misplaced, you can call me at 780-***-****, or send it to:

Kim Cook, MN (C)
c/o Faculty of Nursing
3rd Floor, Clinical Sciences Building
University of Alberta
Edmonton, Alberta T6G 2G3

Your Name:_____

Address:_____

_____

_____

Thank you again for participating!

**Interventionists:**

To: (Interventionists)

Subject: Information letter

*Please respond if you do not wish to participate*
*By responding to the questions I send out in another email, you will indicate your consent*

PROJECT TITLE: Operationalizing Family Centered Practice: Utilization of data from an intervention study

PRINCIPAL INVESTIGATOR: Kim Cook, MN (C)
Faculty of Nursing, 3rd Flr. Clinical Sciences Bldg.
University of Alberta
Ph.: (780) ***-****
Email: **********

CO-INVESTIGATOR/SUPERVISOR: Jane Drummond, Associate Professor
Faculty of Nursing, 3rd Flr. Clinical Sciences Bldg.
University of Alberta
Ph.: (780) 492-6410
Email: ********

ABOUT THE PRINCIPAL INVESTIGATOR:
*My name is Kim Cook, and I am a nurse
*I have permission to do this study as part of masters thesis from the Faculty of Nursing at the University of Alberta.
*the Health Research Ethics Administration Board has given approval to this study and to the change in data gathering media (i.e., email instead of focus group).

REASON FOR THE STUDY:
*the intervention study that you were part of in 1995-1997 used two approaches
-Natural Teaching Strategies
-Cooperative Family Learning
*I am interested in giving you an opportunity to comment on these approaches
-how were they used?
-what was your experience in implementing them?
-how do you think the families experienced the interventions?
-suggestions for improving the interventions and/or the process of implementing them.
*to further develop the interventions
*to inform understanding of Family Centered Practice

BENEFITS OF THE STUDY:
*there are no direct benefits or risks to taking part in this study.
*taking part in this study will not affect your position now or in the future.
*a better understanding of the interventions will be developed

WHAT WILL HAPPEN IF YOU CONSENT:
*I will ask that you return, via email, your responses to the questions I send you and the demographic questionnaire as soon as possible for you. (By sending in your responses, you are indicating your consent).
*I will ask you how you think the interventions were experienced by the families. I will then present you with a brief summary of what I gathered from the families I interviewed, and ask

you to comment on them.
*I will also ask you about your experience in implementing the interventions.
*I will summarize your reported experiences, suggestions, and reflections.
-This information will be proved confidentially (no names) to the researchers from the original project for them to reflect on in order to make changes to the approaches.
*After I have had a chance to analyze your responses, I may need to contact you again by email to clarify, or add to my summary of what was said in our online discussion.
*The expected time commitment on your part is minimal, depending on your answers, and your willingness to share.

SECURITY:
*Only I will have access to my email, and to the hard copy I will make.
*This data will be kept locked with other confidential material
*You will be given a code which will be used instead of your name on any of the documents, research reports, or presentations.
*The information from this study will be kept for at least seven years.
*Information from this study may be used in another study in the future if the investigator gets ethical approval.

COMMUNICATION:
*Taking part in this study is completely voluntary and confidential.
*You do not have to answer any questions you do not want to.
*You can withdraw from this study at any time with no consequences to you. I would just ask that you contact me to let me know.
*If you have any questions about this study, please call/email me.
*You may also call Dr. Janice Lander, Associate Dean, Research (phone: 492-6317) in the Faculty of Nursing if you have any questions or concerns about this study. This person is not connected with the study, or with me.
*Results from this study can be gotten from myself by contacting me, or returning the 'Request for Results' via email.

**Thank you for taking the time to read about my study**

Sincerely,

Kim Cook

Subject: Demographic questionnaire/Request for Results

*Do not reply to 'All recipients'*

INTERVENTIONIST DEMOGRAPHIC QUESTIONNAIRE FOR "Operationalizing family centered practice: Utilization of data from an intervention study"

1. What is the highest level of education that you have completed:
   - -High school diploma_____
   - -Trade school or technical institute_____
   - -Some college/university_____
   - -College diploma_____
   - -University
     - Bacclaureate_____
     - Masters_____
     - Doctorate_____
     - Post-doc._____

2. How would you name your profession?

3. What education do you have in respect of your profession?

4. What is your current job/position?

5. Briefly, what can you tell me about your practice experience in working with families?

**********

REQUEST FOR RESULTS

If you wish to receive a copy of the results from this research, please return this via email, or call me.

Your name:_____

Postal Address (home or work, whichever is best, or both):

THANK YOU FOR PARTICIPATING!!

Subject: Questions

OPERATIONALIZING FAMILY CENTERED PRACTICE...

*Reply to 'all recipients', (there's only the 2 of you) if comfortable doing so, in order to stimulate discussion*

There are 13 questions. Please tell me as much as you can. Contact me if anything needs clarifying.
Thank you!

1a. Can you tell me briefly the story of how you got involved in the original research project (i.e., intervention study using Natural Teaching (NTS) Strategies & Cooperative Family Learning (CFL))?

Are you still involved in the project? If so, how?

1b. What can you tell me about family centered practice (FCP)?

What does 'family centered practice' mean to you (i.e. is it the same or different from what you learned taking part in the original study, etc.)?

1c. Were you familiar with FCP prior to your involvement with the original research project (i.e., the intervention study with NTS & CFL)? Explain.

Have you had any experience with FCP since participating in the original research project?

2. This is a summary of what happened during the intervention study:
-you participated in special 'interventionist training', to prepare you for implementing the two interventions.
-you met with families, most often moms and their child(ren) (even though other family members were encouraged to participate), approximately once every 2 weeks for the duration of the intervention.
-after meeting with families you wrote notes regarding each visit.
-you participated in 'debriefing' sessions with the researcher(s).
-you followed a 'schedule', based on the manuals for each intervention, that was a guideline for what was to happen at each visit.
-you had manuals that also guided what happened at each visit, and helped you in implementing the two interventions.
-most families received both interventions.

.....

Does this represent YOUR experience with these interventions? Explain.

Can you tell me anything else about how the interventions were implemented, or how you implemented them?

3. Do each of the interventions fit with FCP? Explain why/not.
-NTS?

-CFL?

4. How did you incorporate FCP in your dealings with the families?

5. How do you think the *families* experienced the interventions? Can you give me specific examples? (did they find the interventions useful, was one intervention preferred over another, etc.)

6. I am using 4 principles to evaluate the interventions with regards to

'family centered practice':
i. Families are fully involved in decision making and planning, and in the intervention as a whole.
ii. Interventions are geared towards the whole family, not just the child.
iii. Families are able to decide how much/little they wish to participate.
iv. Parents are seen as the experts with respect to their family's needs and priorities.

Would you say these hold true for NTS? (Which items and explain why/why not).

* * * * * * * CFL? ( * * * * * )

7. This is a summary of what the families I interviewed said about how they experienced the interventions at the time:
-generally, very positive about the interventions
-found the interventions helpful for the whole family
-would reccomend the interventions to others
-found the manuals helpful
-found that they (the mothers) were the only ones to try the skills learned in the interventions.
-found the interventionists easy to work with
-found that they weren't having as much fun when they played, because they felt were always trying to teach something.
-found that there wasn't much difference in how the family worked together.
-found they were using (at least some of) the skills learned in the interventions.

.....

How do you respond to these statements taken from the surveys the families filled out immediately after each intervention?

8. This is a summary of what the families I interviewed said about how they experienced the interventions when I interviewed them this fall:

-mothers had a difficult time remembering the interventions without being prompted
-some had a hard time recalling the interventions even when prompted
-the families I interviewed generally considered themselves to not be using the skills from the interventions.
-If mothers stated that they were using some of the skills, they identified skills from NTS.
-NTS was more recognizable to the mothers than CFL, whether or not they were using the skills.
-the interventions were still viewed favourably whether the skills were still being utilized or not.
-participants would still reccomend the interventions to others
-they found that as time passed, they used the skills (at least consciously) less and less.
- examples of reasons given were: "got busy with work..there's no time"; "took what my family needed..what fit for my family"; and, "it didn't work for my family, so we don't use them".
-some participants found they did interact differently with their family members ("It's helped me, help them"; "It's maybe just changed my point of view on how to approach things"; and, "Now (the way) I talk to one of my kids will be completely different form how I talk to the other one"), and yet others didn't since participating in the original study.
-all participants agreed that both the interventions fit with the 4

principles of FCP (the same as what I presented to you).
-there were no negative comments re: the interventions, and no changes were recommended.
-participants found it hard to remember where things they do/have learned came from.
-some participants thought that they may use some of the skills, but aren't consciously aware of it.
-the schedule, and flexibility of the interventionists, fit with the participants (i.e., coming every 2 weeks was about right).

.....

How do you respond to these statements?

9. What do the families reported experiences, in combination with your own experience with the interventions, mean for:
-your own work?

-implementing NTS?

-implementing CFL?

-the implementation of family centered practice in general?

10. Do you have any suggestions for improving the interventions themselves? Explain.
-NTS?

-CFL?

11. Can you give me examples of changes you would suggest to others in implementing:
-NTS?

-CFL?

-family centered practice?

12.Is it possible, or even desirable, to make NTS & CFL more family centered? Explain.

13. Is there ANYTHING else you'd like to say about implementing NTS & CFL in the original research project, the interventions themselves...

---

Thank you for taking the time to answer these questions. I appreciate your time & effort VERY much!

I wish you a very happy and peaceful holiday season.

Kim Cook

**Researchers:**

Subject: Information letter (fwd)

*Please respond if you do not wish to participate*
*By responding to the questions I send out in another email, you will indicate your consent*

PROJECT TITLE: Operationalizing Family Centered Practice: Utilization of data from an intervention study

PRINCIPAL INVESTIGATOR: Kim Cook, MN (C)
Faculty of Nursing, 3rd Flr. Clinical Sciences Bldg.
University of Alberta
Ph.: (403) 967-3570
Email: kgcook@gpu.srv.ualberta.ca

CO-INVESTIGATOR/SUPERVISOR: Jane Drummond, Associate Professor
Faculty of Nursing, 3rd Flr. Clinical Sciences Bldg.
University of Alberta
Ph.: (403) 492-6410
Email: jane.drummond@ualberta.ca

ABOUT THE PRINCIPAL INVESTIGATOR:
*My name is Kim Cook, and I am a nurse
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-how were they used?
-what was your experience in implementing them?
-how do you think the families experienced the interventions?
-suggestions for improving the interventions and/or the process of implementing them.
*to further develop the interventions
*to inform understanding of Family Centered Practice

BENEFITS OF THE STUDY:
*there are no direct benefits or risks to taking part in this study.
*taking part in this study will not affect your position now or in the future.
*a better understanding of the interventions will be developed

WHAT WILL HAPPEN IF YOU CONSENT:
*I will ask that you return, via email, your responses to the questions I send you and the demographic questionnaire as soon as possible for you. (By sending in your responses, you are indicating your consent).
*I will ask you how you think the interventions were experienced by the families. I will then present you with a brief summary of what I gathered from the families I interviewed, and ask you to comment on them.
*I will also present you with a summary of what the interventionists

had to say, and ask for your comments.
*I will summarize your reported experiences, suggestions, and reflections.
*After I have had a chance to analyze your responses, I may need to contact you again by email to clarify, or add to my summary of what was said in our online discussion.
*The expected time commitment on your part is minimal, depending on your answers, and your willingness to share.

SECURITY:
*Only I will have access to my email, and to the hard copy I will make.
*This data will be kept locked with other confidential material
*You will be given a code which will be used instead of your name on any of the documents, research reports, or presentations.
*The information from this study will be kept for at least seven years.
*Information from this study may be used in another study in the future if the investigator gets ethical approval.

COMMUNICATION:
*Taking part in this study is completely voluntary and confidential.
*You do not have to answer any questions you do not want to.
*You can withdraw from this study at any time with no consequences to you. I would just ask that you contact me to let me know.
*If you have any questions about this study, please call/email me.
*You may also call Dr. Janice Lander, Associate Dean, Research (phone: 492-6317) in the Faculty of Nursing if you have any questions or concerns about this study. This person is not connected with the study, or with me.
*Results from this study can be gotten from myself by contacting me, or returning the 'Request for Results' via email.

**Thank you for taking the time to read about my study**

Sincerely,

Kim Cook

Subject: Demographic questionnaire/Request for Results

*Do not reply to 'All recipients'*

Researcher DEMOGRAPHIC QUESTIONNAIRE FOR "Operationalizing family centered practice: Utilization of data from an intervention study"

1. What is the highest level of education that you have completed:
   -University
      Bacclaureate_____
      Masters_____
      Doctorate_____
      Post-doc._____

2. How would you name your profession?

3. What education do you have in respect of your profession?

4. What is your current job/position?

5. Briefly, what can you tell me about your practice experience in working with families?

**********

REQUEST FOR RESULTS

If you wish to receive a copy of the results from this research, please return this via email, or call me.

Your name:_____

Postal Address (home or work, whichever is best, or both):

THANK YOU FOR PARTICIPATING!!

Subject: Questions (fwd)

OPERATIONALIZING FAMILY CENTERED PRACTICE...

There are 13 questions. Please tell me as much as you can. Contact me if anything needs clarifying.
Thank you!

1a. Can you tell me briefly the story of how you got involved in the original research project (i.e., intervention study using Natural Teaching (NTS) Strategies & Cooperative Family Learning (CFL))?

Are you still involved in the project? If so, how?

1b. What can you tell me about family centered practice (FCP)?

What does 'family centered practice' mean to you (i.e. is it the same or different from what you learned taking part in the original study, etc.)?

1c. Were you familiar with FCP prior to your involvement with the original research project (i.e., the intervention study with NTS & CFL)? Explain.

Have you had any experience with FCP since participating in the original research project?

2. This is a summary of what happened during the intervention study:
-you participated in special 'interventionist training', to prepare you for implementing the two interventions.
-you met with families, most often moms and their child(ren) (even though other family members were encouraged to participate), approximately once every 2 weeks for the duration of the intervention.
-after meeting with families you wrote notes regarding each visit.
-you participated in 'debriefing' sessions with the researcher(s).
-you followed a 'schedule', based on the manuals for each intervention, that was a guideline for what was to happen at each visit.
-you had manuals that also guided what happened at each visit, and helped you in implementing the two interventions.
-most families received both interventions.

.....
**The interventionists added only that each family was unique and that even though certain material was to be covered, they tried to make it as applicable as possible, in order for the information to be useful. The bi-weekly (approximately) visits often followed the pattern of listening to parental concerns, and then covering the intervention material and practicing skills.

Does this represent YOUR experience with these interventions? Explain.

Can you tell me anything else about how the interventions were implemented (or meant to be implemented)?

3. Do each of the interventions fit with FCP? Explain why/not.
-NTS?

-CFL?

The interventionists stated that the research aspect of the project understandably put some limitations on the interventions with regard to FCP,

but that on
the whole they were family centered (CFL was thought to be more so than NTS because of the flexibility parents had in choosing the situations and individualizing content; NTS was seen as necessarily more 'regimented'). "Truly family-focused intervention provides parents with more of a smorgasbord of services and information, and allows the family to mix and match whatever suits their strengths and needs at the time". "We could work on any situation the family chose to work on. I think this meant to the family a more immediate meeting of need...I think this was very motivating to families."

How do you respond to these statements?

4. How did you incorporate FCP in developing the manuals and the interventions?

The interventionists felt that the most useful skill in being family centered is good listening to find out what the family wants/needs.

5. How do you think the *families* experienced the interventions? Can you give me specific examples? (did they find the interventions useful, was one intervention preferred over another, etc.)

The interventionists felt that the families that practiced the skills in NTS generally found their relationship with their child was enhanced, although not all families reached 'fluency' (even with much practice while the interventionist was present). Severe crisis was seen as being a major factor here. The children enjoyed NTS very much. The section of NTS that dealt with "A new look at challenging behaviour", and the CFL, were seen as involving the whole family more and helped them address issues they were currently facing.

CFL was seen as being liked by the parents, although the parents likely wouldn't go through all the steps on their own, after finishing the intervention. Some families practiced enough that the skils became 'second nature'.

Both interventions took time to seem beneficial...after building a trusting relationship, and teaching new skills, or bringing out family skills and looking at them positively. Depending on the family, one intervention seemed better recieved than the other. Some families found the whole process a waste of time, not getting 'on board'. Some of the skills introduced to parents were skills they were already quite good at which parents found reassuring (that they had many positive, useful skills and some control over decisions made).

How do you respond to this?

6. I am using 4 principles to evaluate the interventions with regards to 'family centered practice':

i. Families are fully involved in decision making and planning, and in the intervention as a whole.

ii. Interventions are geared towards the whole family, not just the child.

iii. Families are able to decide how much/little they wish to participate.

iv. Parents are seen as the experts with respect to their family's needs and priorities.

Would you say these hold true for NTS? (Which items and explain why/why not).

" " " " " " " CFL? ( " " " " " )

The interventionists responded that generally both NTS & CFL met the 4 criteria, although item i was weak for both (with acknowledgment of the research agenda). The interventionists did what they could to build in

flexibilty and family involvement. Also, parents might view NTS as being more child focused, and CFL more adult focused (children's input not used as much, although when possible a child's idea's were used).

7. This is a summary of what the families I interviewed said about how they experienced the interventions at the time:

-generally, very positive about the interventions
-found the interventions helpful for the whole family
-would reccomend the interventions to others
-found the manuals helpful
-found that they (the mothers) were the only ones to try the skills learned in the interventions.
-found the interventionists easy to work with
-found that they weren't having as much fun when they played, because they felt were always trying to teach something.
-found that there wasn't much difference in how the family worked together.
-found they were using (at least some of) the skills learned in the interventions.

The interventionists added that they thought the manuals probably wouldn't be utilized by the families one the interventions were finished; some families did think the skills were fun, and were surprised by how much could be learned through playing & having fun. Also, when only one parent of a two parent family participated, this tended to influence the (mother's) feeling that there wasn't much difference in how the family worked together.

How do you respond to these statements taken from the surveys the families filled out immediately after each intervention?

8. This is a summary of what the families I interviewed said about how they experienced the interventions when I interviewed them this fall:

-mothers had a difficult time remembering the interventions without being prompted
-some had a hard time recalling the interventions even when prompted
-the families I interviewed generally considered themselves to not be using the skills from the interventions.
-If mothers stated that they were using some of the skills, they identified skills from NTS.
-NTS was more recognizable to the mothers than CFL, whether or not they were using the skills.
-the interventions were still viewed favourably whether the skills were still being utilized or not.
-participants would still reccomend the interventions to others
-they found that as time passed, they used the skills (at least consciously) less and less.
  - examples of reasons given were: "got busy with work..there's no time";
"took what my family needed..what fit for my family"; and, "it didn't work for my family, so we don't use them".
-some participants found they did interact differently with their family members ("It's helped me, help them"; "It's maybe just changed my point of view on how to approach things"; and, "Now (the way) I talk to one of my kids will be completely different form how I talk to the other one"), and yet others didn't since participating in the original study.
-all participants agreed that both the interventions fit with the 4 principles of FCP (the same as what I presented to you).
-there were no negative comments re: the interventions, and no changes were recommended.
-participants found it hard to remember where things they do/have learned came from.
-some participants thought that they may use some of the skills, but

aren't consciously aware of it.
-the schedule, and flexibility of the interventionists, fit with the participants (i.e., coming every 2 weeks was about right).
-one mom said things (i.e., skills) were starting to be refreshed as her younger child was reaching the age her older one had been when starting the interventions.
-barriers to FCP were identified as: partners (in this case, fathers) welcome, but didn't participate at their own choice or circumstances (working out of town, etc.). Left mom with the work load, and keeping up with the day to day, plus keeping up with new skills, and practicing them, meant mom dropped something, and that was keeping up with the interventions.

How do you respond to these statements?

9. What do the families' and interventionists' reported experiences, in combination with your own
experience with the interventions, mean for:
-your own work?

-implementing/developing NTS?

-implementing/developing CFL?

-the implementation of family centered practice in general?

The interventionists had a few suggestions, and responded that they felt they had gained a
great deal in the way of knowledge & skills from participating in the project (eg., adding CFL to their repertoire of problem solving models). There doesn't appear to be any negative effects, only positive.
Re: NTS-each family got positive feedback which is always welcome; provided positive time between parent and child at least while the interventionist was there; the option of more time to work on chapters as felt necessary; incorporating video/feed back into application of the interventions. Add more to challenging behaviour, or provide references, or readily available resources. The manual had mostly examples for babies which make it difficult for some parents to see the use of these skills with their older children. It lead them to feel the interventions was for babies, and that their children were past this. The interventionists did what they could to provide more applicable examples, and encouraging lots of practice.

Re: CFL-more time...; incorporating video/feedback...Other examples besides Billy's Boots, in case family's don't relate to that one. More practice sheets for skills that need more practice (often perspective taking & conflict management). Some skills needed more time than available... The interventionists were surprised that the families didn't remember as much about the CFL, especially when reminded of the WE CAN. It didn't surprise the interventionists that the 'lingo' of CFL didn't stick.

Re: Implementing FCP in general-The interventionists felt they had gained a greater appreciation of families as more complex and intricate systems, and that they have a greater repertoire of skills to offer families. Families were able to take what fit with their family. The parents appreciate being treated as equal partners and being listened to without being judged.

10. Do you have any suggestions for improving the interventions themselves? Explain.
-NTS?

-CFL?

11. Can you give me examples of changes you would suggest to others in implementing:
-NTS?

-CFL?

-family centered practice?

The interventionists suggested the following for:

*NTS-try lots of different activities for practicing skills so that one activity does not become the only activity to enhance turn taking or expansion, etc. Let the family choose the activities while trying to show how these skills can be used with a great variety of activities. Practice a skill until it is comfortable for a family, going back and forth between skills when necessary.

*CFL-focus on the skills that seem to work for the family and stay positive.

*FCP-don't follow a strict protocol so you can be more family centered. Keep a very open mind. Invite and encourage parents to contribute feedback, input, perceptions at every visit. Check, and check again. Positively affirm their participation, also respect their boundaries. Parents (and some professionals) are not used to being valued as 'experts'. People working with families can help with this paradigm shift by encouraging parents in, and affirming, their partnership with professionals. Also, it might be beneficial for anyone working with families to have some background in adult education as well as child development and learning.

12.Is it possible, or even desirable, to make NTS & CFL more family centered? Explain.

The interventionists responded that it is up to the interventionist to present the intervention in a more family centered way, and that it would be beneficial if families were allowed more flexibility in the rate at which the new information was covered.

13. Is there ANYTHING else you'd like to say about implementing NTS & CFL in the original research project, the interventions themselves...

The interventionists responded that it would be ideal to work with families of new babies through the pre-school years, especially with high-risk families. Many parents voiced that they wished they had learned the NTS skills when they had started parenting rather than four years later. Ongoing optional support is needed for these families to access based on their needs.

---

Thank you for taking the time to answer these questions. I appreciate your time & effort VERY much!

Kim Cook

To: (Interventionists)

Subject: Addendum to FCP questionnaire

Hello. As I have not yet received responses from the researchers, I thought maybe it wasn't too late to send this.

I recently received an unexpected response from a third interventionist. I apologize for sending this out late, but thought you may be interested....

If you can respond to this summary along with the other questions I sent out, it would be much appreciated.

Thank you.

Kim
**********"

SUMMARY:

-FCP means interventions delivered in the home, with all family members present
-families cancelled visits, so quite often 2 weeks intervention was delivered in one visit. This interventionist felt, and she reported families mentioned to her, that the commitment of meeting every 2 weeks was difficult. Some families reported to her that they didn't realize the time commitment involved when they agreed to be part of the project.

And, as alluded to by the other interventionists:
-in a 2 parent family, spousal support was seen as being an important factor in implementation of the skills.
-one of the most difficult concepts to convey was that families could have fun when they played, even when trying to teach something.
-the statement "some participants thought that they may use some of the skills, but arent' consciously aware of it", would be the case for more participants than stated it.
-more repetition of skills
-outside of a research project, families should be more involved in the decision making & planning to individualize the interventions.

---

Thank you again.
**********
Kim Cook, BScN, MN(C)

Appendix G

**Ethical Approval**

University of Alberta
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Rehabilitation Research Centre

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*UNIVERSITY OF ALBERTA HEALTH SCIENCES FACULTIES, CAPITAL HEALTH AUTHORITY, AND CARITAS HEALTH GROUP*

## HEALTH RESEARCH ETHICS APPROVAL

**Date:** April 1998

**Name(s) of Principal Investigator(s):** Kim Cook

**Organization(s):** University of Alberta

**Department:** Graduate Studies; Faculty of Nursing

**Project Title:** Operationalizing Family Centered Practice: Utilization of Data from an Intervention Study.

The Health Research Ethics Board has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the patient information material and consent form.

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval.

Sharon Warren

Dr. Sharon Warren
Chair of the Health Research Ethics Board (B: Health Research)

File number: B-040498-NSG

Health Research Ethics Board | biomedical research | health research

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*UNIVERSITY OF ALBERTA HEALTH SCIENCES FACULTIES,*
*CAPITAL HEALTH AUTHORITY, AND CARITAS HEALTH GROUP*

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for Dr. Sharon Warren
Chair of the Health Research Ethics Board (B: Health Research)

File number: B-040498-NSG

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